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PREFACE

BLINDNESS 1974-75 is the eleventh issue of an annual published by the American Association of Workers for the Blind. It is designed to provide a forum for important and timely articles, treated in depth, in our own field and in related fields. Experts in the many categories of work with blind persons are commissioned to conduct the essential research and prepare the articles so that their continuing value will be assured. BLINDNESS should reflect the movement of human thought in respect to blindness and stimulate original thinking and excellence of practice in the field.

In accord with the above objective, BLINDNESS was originally intended to include some of the significant papers presented at the AAWB conventions. This issue of BLINDNESS, more than any other, has included papers presented at regional and biennial conventions. The Publications Committee hopes to continue this practice.

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WHAT IS BLINDNESS?*

By

Berthold Lowenfeld, Ph.D.

"What is Blindness?" is a recondite and enigmatic question, as simple as it may appear and as ready as some answers to it may seem to be. Dictionaries give definitions and list a great variety of meanings for the word "blind" and "blindness." The OXFORD ENGLISH DICTIONARY lists as the first explanation "destitute of the sense of sight, whether by natural defect or by deprivation," but it contains full four columns that further dissect the various meanings of the word. There are other dictionaries that give different definitions, such as "without the power of sight," "not able to see," etc. There is also an "official" definition of blindness which sets visual limits in terms of Snellen distance measurements and field of vision. Though it is widely accepted, it is also widely criticized. But I am sure you did not come to hear me elaborate on this aspect of the question although it has its interesting ramifications.

Before turning to the discussion of what blindness is to those who are directly concerned with it, either because they are blind themselves or are working with the blind, I want to point out, on one example, how many facets there are to the question. To those who work with the blind, the visual impairment denoted by the term "blindness" varies according to at least four variables: (1) the degree of sight retained, (2) the age at onset of blindness, (3) the time elapsed since the onset of blindness, and (4) the cause and the kind of onset of blindness.

The degree of sight ranges from nil in total blindness to a considerable amount of sight, 20/200 Snellen distance vision, equivalent to a loss of 80 percent, according to the ophthalmological definition. Individuals vary in their abilities to make functional use of whatever sight they have and thus a personal variable enters that must be considered for all practical purposes. The problem of replacing the currently used definition of blindness which is based on distance vision measured by the Snellen chart and does not include near vision, so important for the individual's pursuit of life, is a challenging one. Little progress has been made toward its solution, except for the recognition that a more functional definition is needed.

The age at onset of blindness is important because those who are congenitally blind or become blind when younger than about five years do not retain a workable visual imagery. This means that they must either from birth or from early childhood on adjust to the world of the seeing, a world that is in its visual aspects not experientially known to them. Those who become blind later in life must adjust to the demands of the world of the seeing which they have known and can more or less clearly remember. They also know what they have lost and the emotional effect of their loss varies with their personality.

The time elapsed since the onset of blindness is an important factor because it must be considered in judging the adjustment of the individual and also in providing educational or rehabilitative assistance. Obviously the person who has lived with his blindness for a long time is in a different position than one who has only recently become blind.

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*Keynote address delivered at the Mid-Atlantic States Regional Conference of the AAWB, Philadelphia, 1974.

The cause and kind of onset of blindness are related factors because the cause of blindness determines whether the onset was slowly developing or sudden. The former puts the person in a prolonged state of insecurity and uncertainty, while sudden onset causes a shock from which the individual recovers according to his ego-strength and environmental support. The cause of blindness also indicates whether an individual's health in general is affected, as in such systemic diseases as diabetes or tuberculosis, or whether the pathological process is confined only to the eyes. Furthermore, the cause of blindness will also dictate what treatment if any may be needed and what physical care must be taken of the eyes. The answer to the question "What is Blindness?" for the individual client will depend on these variables and they will to a certain extent determine what action you, as workers with the blind are going to take in planning with them either for their education or rehabilitation.

The widely and also by me highly Reverend "Father Tom," the Reverend Thomas J. Carroll, entitled his book BLINDNESS, WHAT IT IS, WHAT IT DOES, AND HOW TO LIVE WITH IT and the "WHAT IT IS" concerns us today, and not only today. In asking the question, what blindness is, I believe we should first look at the answers that those who are themselves blind have given us. By the way, this approach has been sorely neglected by workers for the blind to the detriment of the whole field. There are blind people in most specialties within work with the blind, may it be educational, rehabilitative, or social, who are professionally trained and capable. They are by their own experience of blindness better qualified to have their say on problems of the blind and of blindness than many others who were propelled or propelled themselves into positions of decision-making.

Among the many blind authors who have discussed the question of what blindness is, there are two outstanding experts whose positions appear to be diametrically opposed. They are representative of two evaluations of blindness that are widely held among the blind and expressed in variations by many blind people. There are those who feel that they must belittle the effects of blindness and therefore want to have blindness considered only as a nuisance or inconvenience. One can hear many statements to that effect made, most often in order to impress an audience of sighted persons who are likely to overestimate the gravity of blindness. I have doubts that describing blindness as a nuisance or in equivalent terms has any positive effect. I suspect that in most cases sighted people consider it unrealistic and self-deceiving propaganda. Even worse, they may believe that the blind person who makes such statements has motives that are more congruent with their own prejudices and negative attitudes toward the blind. It is in a way surprising that such a researchable problem has not been investigated and it would be interesting to devote some research to it. The foremost representative of this minimizing interpretation of blindness was Jacobus tenBroek. Many of us have heard him describe blindness as a nuisance, inconvenience, or annoyance or have read his speeches in which he so described it. This raises a semantic problem because all three words, nuisance, inconvenience, and annoyance, cover a wide range of severity of the condition they are supposed to characterize. Nuisance, for instance, is defined in Webster's NEW COLLEGIATE DICTIONARY and in the OXFORD ENGLISH DICTIONARY as injury, hurt, harm, annoyance. Blindness is certainly an injury, not only to the eyes, but to the human being as a whole. Thus we come by a somewhat circuitous route to an acceptable and realistic explanation of tenBroek's description. He must have meant it this way, because it is in line with the statement that can be found in his main work dealing with blindness and the blind, HOPE DEFERRED (tenBroek and Matson, 1959): "In simple terms, the thesis is that the blind as a group are mentally competent, psychologically stable, and socially adaptable; and that their needs are therefore those of ordinary people, of normal men and women, caught at a physical and social disadvantage (p. 1)."

On the other side are those blind people who think of blindness as an extreme handicap. They are represented by Thomas D. Cutsforth, the social psychologist, who stated: "It is generally supposed that blindness represents the mere absence or impairment of a single sense. On the contrary, blindness changes and utterly reorganizes the entire mental life of the individual. The earlier this frustration occurs, the greater the reorganization that is demanded . . . (1933, p. 2)." I said before that tenBroek's and Cutsforth's interpretations appear to be opposed, in reality they are not so far apart. Cutsforth who stressed the importance of reorganization said about this in a later publication (1950) that the blind individual "must mature to accept himself as he is and to live in his social world as it is. Many individuals have found this pattern for themselves, and when they have found it, they have made the joyous discovery that the condition of blindness is the least important thing about themselves, and that it is of no importance at all to others (p. 180)." This means that the well-adjusted blind person finds that blindness is "the least important thing" in the make-up of his personality. The difference between tenBroek and Cutsforth is thus only in the latter's stress on reorganization and acceptance of the self as it is, which constitutes what is commonly called adjustment to the handicap.

Chevigny (1946 and 1950), another blind writer, shares Cutsforth's adjustment thesis, and elaborates particularly on the social and physical reorganization required by the onset of blindness, always making the point of individual differences according to personality characteristics. Chevigny and Braverman (1950) emphasized the psychoanalytic interpretation of blindness. The equation of the eye with the sex organs has a long history in mythology and in symbolic literature, as Monbeck (1973) has more recently pointed out. This is the basis of castration anxiety which can be activated by any threat of physical injury, but is more potently aroused by loss of sight because of the equation of the eye with sex organs. The most active psychoanalyst in work with the adult blind, H. Robert Blank, has given us a useful, even if "sketchy outline of the principal relevant concepts" of the psychoanalytic interpretation:

1. the unconscious association of the eye and vision with omnipotence;
2. the unconscious significance of the eye as a sexual organ, including the equation of eye with mouth and genital;
3. the unconscious significance of the eye as a hostile destructive organ, the equation of eye with devouring mouth and with piercing phallus;
4. the unconscious significance of blindness as castration, as punishment for sin (more accurately, for fantasies of sin);
5. the unconscious involvement of the eye in conflicts of envy, greed, exhibitionism and scopophilia (1971, p. 183).

Let me insert here that Freud himself referred in 1919 to the childhood fear of hurting or losing the eyes and stated that anxieties about the eyes and the fear of blindness are frequently substitutes for fear of castration (1947, vol. 12, p. 243).

In a recent paper Emerson Foulke (1972) discussed cogently the far-reaching implications of the sensory and motor limitations of blindness for perception and cognition. He proposes an interpretation of blindness in terms of behavioral information theory. The information processing system differs individually in sensory, motor, processing, and storage capacity. If the system, originally programmed for a full range of sensory input, loses vision as an information gathering and behavior regulating source, it must be reprogrammed and formerly unused stimulation must be utilized for regulating behavioral sequences. In congenital blindness the central nervous system is from the beginning programmed by nonvisual experiences. This in a nutshell is Foulke's thesis and he contends that it is testable and practical.

This short review of the blindness interpretations of psychologists and sociologists who are themselves blind shows that they consider blindness an impairment that requires adaptation, adjustment, reorganization, or reprogramming. Blindness makes special demands on the individual but the continuity of his existence and of his personality have never been questioned by any of these interpretations.

This remained to be done by some sighted interpreters of blindness, among whom we find a scene of greater and sharper contrasts. Here is perhaps the place to discuss the tragedy or disaster concept of blindness which Jernigan described thus: "I think it is clear that the disaster concept is widespread alike in popular culture and in the learned culture of the professionals. Moreover, I would submit that the concept itself is the real disaster--the only real disaster that we blind people have to live with--and that when we can overcome this monstrous misconception, we shall ring down the curtain forever on the fictional drama entitled 'The Tragedy of Blindness' (The First Thirty Years, p. 7)."

Two examples demonstrating the disaster concept among professionals in work with the blind are the book BLINDNESS, WHAT IT IS, WHAT IT DOES, AND HOW TO LIVE WITH IT (1961) by the Reverend Thomas J. Carroll, and A PSYCHIATRIST WORKS WITH BLINDNESS (1958) by Louis S. Cholden, M.D. Carroll entitled the first chapter of his book "The Sighted Man Dies" and starts it out with the terse statement "Loss of sight is a dying." Although he softens this later by saying that "In a sense, we die many deaths in our lifetime; life is a series of dyings," the emotional and cognitive impact of this dictum is devastating and by no means relieved by the discussion of the 20 losses caused by blindness on which the next chapters elaborate. Relief comes only when Rehabilitation and Restoration are discussed and show how the 20 losses can be alleviated by the fiat of restoration and rehabilitation. There is so much sensible and valuable in Carroll's book that one is tempted to ask why he needed the "dying" concept and the finality of "losses" to explain blindness. It may be that the dying and resurrection idea with which he as a Catholic priest was brought up exerted an influence that carried over into our field. A milder view, though still extreme beyond reality, was taken by Dr. Louis S. Cholden, a psychiatrist. He wrote, "This concept of blindness as death, while overly grim, is not altogether inappropriate, for the patient must indeed 'die.' He must die as a sighted person and be reborn as a blind person. He must learn to live all over again in a new world, and with a new set of sensory instruments. In other words, he must learn to accept his blindness as a condition of his life, as he accepts the relative weakness of his left hand and the air that he breathes (p. 18)." Later on Dr. Cholden who applied the Freudian concept of mourning at a loss to reactions on becoming blind, made this statement: "The degree of damage to the ego and the capacity to recover from the initial shock reaction will depend on the degree of ego-strength and maturity attained at the time of the disability. The way the individual has learned to cope with his major life problems and emergencies antedating his blindness will largely determine his ego-recovery capacity as far as blindness is concerned, assuming, of course, that the external obstacles are not too great (p. 74)." This statement recognizes the importance of personality as a continuum and thus contradicts the "dying and rebirth" concept.

It is in line with the thinking of most psychologists who have concerned themselves with blindness and with reactions and adjustment to it.

Before dealing with these views, I want to discuss my position on the "Dying and Rebirth" aspect, so prominently stressed by Carroll. There is no doubt that ever since biblical and even prebiblical times blindness was equated with death, as Monbeck (1973) has well documented. But this is folklore, mythology, and opinion. It is something entirely different when a recognized expert in the field of blindness rehabilitation interprets the meaning of blindness in such extreme terms. This concept questions the continuity and indeed the viability of life after the onset of blindness. In line with it is the enumeration of 20 losses caused by blindness, mind you losses and not limitations! Death and loss have a finality that most of us cannot recognize as an effect of blindness and not a single blind psychologist has written about it in these terms. It is an entirely speculative assumption which I consider as detrimental to the interest of the blind as the popular "tragedy or disaster concept." I am, of course, aware that Carroll postulates that rebirth can take place through a total restoration process and that the losses can be made up to a certain extent by rehabilitation, but this does not mitigate the equation of blindness with dying, nor does it turn losses into limitations. I also agree fully with Foulke's (1972) critique of Carroll's theory: "That the adjustment to adventitious blindness entails a dying as a sighted person and a rebirth as a blind person is, in my opinion, a conceptual approach that is not very helpful. First, it fails to encompass and organize information that would be useful to the educator and rehabilitator. Further, because it is an inadequate formulation, it misdirects its adherents in the search for new information (p. 33)."

But now to those who have recognized that blindness is a cause of limitations and demands adjustment because the blind individual must live in a society in which sight plays a dominant role. We have already discussed the position taken by psychologists who were themselves blind, but there are many others who have done research and written about blindness. They all recognize that blindness, that is lack or loss of sight, is a severe sensory impairment that affects the person as a whole. It demands, because of the effects of the limitations it imposes and because of the environmental reactions to it, adjustments on the sensory, emotional, and socioeconomic level. These the individual achieves according to his personality and his capacities. Such researchers and authors as Bauman (1954, 1966), Cowen, et al. (1961), Lowenfeld (1950, 1971), Monbeck (1973), and Sommers (1944) have made contributions which in addition to those of the previously discussed blind authors have made the condition of blindness better understood. I said "better understood" because a full understanding eludes the sighted who cannot put themselves completely into the experiential and reactive position of the blind person. This is not an uncommon phenomenon in psychology. All of child psychology--and there is a good deal of it--is based on the fact that adult persons, though they all have once been children, cannot experience childhood and its ways of sensing, feeling, and thinking. Volumes by the thousands have been written about it and those who come closest to an understanding of child psyche are perhaps not psychologists but poets.

One word more about "adjustment." We talk generally about adjustment to blindness and mean by it the process that goes on in the individual who has lost his sight. For the congenitally blind, it is obviously not adjustment to blindness, but adjustment to the world of the seeing. Bauman and Yoder (1966) expanded the concept of "adjustment to blindness" when they stated the need "to consider 'adjustment' as something much more complex than merely 'adjustment to blindness.' The steady trends in the histories of many of these people, the patterns which were often evident before visual loss, compel us to feel that we are observing not adjustment to blindness, but adjustment under the stress of blindness. Therefore, all research related to stress is at least indirectly related to problems of blindness and needs very thoughtful consideration by any truly professional worker with blind people (pp. 106-107)." In other words, blindness acts as a stress-producing factor and it is to this stress to which the individual must adjust.

This is a very interesting and valid proposition which deserves to be more closely investigated. Offhand I would agree that for instance the apprehension of blind people who feel that they are continuously under observation by the sighted and never know when this begins or ends, is a stress factor. Also the feelings that they are constantly under pressure to "live up" to the expectations of the seeing and must "achieve" and "deliver" are stressful. In raising the question of how blind people cope with this stress, we must consider the often observed fact that adjustment to blindness does not produce in the blind an unusual amount of those psychosomatic diseases which are assumed to result from stress, such as stomach ulcers and heart disease. Many observers have to the contrary noted that these seem to occur less frequently among the blind. Cutsforth noticed this in 1939 when he wrote: ". . . it might be illuminating for those of us who have had many years of association with large numbers of blind persons to count on our fingers the number of cases we have observed of peptic ulcers, hypertensive heart and circulatory disturbances, various hysterical paralyses, anaesthesias, and conditions involving vasomotor instability among blind persons (1951, p. 240)." He noticed that among the seeing these occur in about 30 percent of the population, and adds, "But do we, in our list of blind acquaintances, find anywhere near such a high proportion of nervous disorders (p. 241)?" Cutsforth who never rested with the statement of a problem furnished a psychiatric explanation of it: He believed that "blindness which produces a frustrated life also furnished its own major pathological symptom (p. 240)." In other words, "The state of invalidism itself is a sufficient escape from all real worries . . . (p. 241)." Thus, he suggested that blindness itself provides a sufficient excuse for any lack of success, so that the blind person does not have to use any other imaginary or hysterical symptoms. Since the 1930's great progress has been made in the economic integration of the blind placing them more frequently in competitive life situations. It would be interesting to know whether Cutsforth's assumption of a lower susceptibility of the blind for psychosomatic diseases can still be upheld.

Finally, let me share with you my thinking about the description of blindness as a disability, a defect or deficiency, an impairment--and as a handicap. Disability, defect, impairment mean essentially the same, a fault in the functioning of a physical or sensory ability. A handicap is, or may be, the result of such a malfunctioning depending upon the situation in which it is experienced. The degree or extent of a malfunction may be quantified, that is it can be expressed by some measurement, in the case of visual impairment by the Snellen chart or in percentage form (80 percent loss of vision). A handicap, on the other hand, is situation-dependent and therefore variable. It is justified to talk, for instance, about visually handicapped children in connection with their education because the effects of blindness on the cognitive functions of children (Lowenfeld, 1971) are such that they put them at a distinct disadvantage so far as their education is concerned. That many of these children are able to overcome their educational handicap by their own efforts and ingenuity and by environmental support, is another story. In contrast, it would be unjustified to talk about blindness as an occupational handicap because in some occupations it is no handicap at all. The specific situation in which the blind person is expected to function and his own adequacy in coping with it determines whether blindness is a handicap to him. It remains a disability, defect or impairment regardless of any situational relation.

In conclusion now, what can we say is blindness? It is a loss or serious impairment of vision that demands adjustment in order to reduce its handicapping effects. Education and rehabilitation are the most important means of adjustment. Their success, however, is basically dependent upon the strengths of each individual.

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FOUR BLIND LAWMAKERS

By

Peter Brock Putnam

Ever since the idea of progress took hold in the Eighteenth Century, the men of each succeeding generation have been tempted to eulogize the enlightenment and advancing science and technology of their own age over the relative ignorance and backwardness of the past. As we who work for the blind enter the final quarter of the Twentieth Century, we may well take pride in the growth of specialized services and technology that have enabled blind men and women to enter the mainstream of American life in ever increasing numbers. But we ought not to allow our gratification with the present to dull our appreciation of the past.

Four pioneers who carved out careers of real distinction with few of our modern advantages were Henry Fawcett, Thomas Gore, Thomas Schall and Ian Fraser. They have much to teach us about the problems and potentialities of blindness. Spread over three generations, all four were born in the Nineteenth Century. All began life with normal sight and were totally blinded by accidents in their youth or early manhood. All were blessed in their marriages to exceptionally intelligent, determined, and devoted wives. And all overcame blindness to become distinguished lawmakers. The two Englishmen, Fawcett and Fraser, won seats in the House of Commons, while the Americans, Gore and Schall, were elected to the United States Senate.

Henry Fawcett, the earliest of the four, was born in 1833, the son of a successful draper who was also the mayor of Salisbury. He set his sights on a political career when he was only fourteen and never waivered in his ambition. Entering Peterhouse College in Cambridge at nineteen, he was an unusually tall, likeable lad with an infectious laugh, a powerful physique, and a zest for debate. He played cricket, tennis, and rowed on the crew. He was no classical scholar, but his debating prowess won him a fellowship worth two hundred and fifty pounds a year.

After graduation, he entered Lincoln's Inn to study law, but severe eyestrain forced him to postpone his studies, when his doctor ordered him not to read for an entire year. This was only the precursor of far worse to come. In September of 1858, during a partridge hunt, a shot from his own father's gun pierced the tinted spectacles Henry was wearing, and one pellet buried itself in each eye. He was just twenty-five.

Years later, during an election campaign, Fawcett claimed that he "made up his mind in ten minutes" to pursue his political ambitions in spite of blindness, but he suffered from depression and doubt in the early aftermath of the accident. Letters from his many well-meaning friends advised resignation to the half life of a blind man and rankled his proud spirit. The return of limited light perception tormented him with uncertain hope until the failure of surgery left him in total darkness.

In the interim, he had returned to Cambridge and sought to resume as normal a life as possible. He had to give up writing with his own hand, so he hired a secretary to take dictation and to read aloud. He organized a crew and rowed on the Cam three times a week. He became such an enthusiastic walker that sighted companions had difficulty keeping up with his long strides. In the winter, he went ice skating, holding one end of a stick while a sighted friend held the other. Into his forties, he enjoyed skating expeditions that covered as much as fifty miles in a day. He rode horseback, too, but his favorite recreation was fishing. He would wade fearlessly out into a river, cast his fly, and land salmon or trout with a skill that was the envy of many a sighted angler.

He was a fine conversationalist and took an active part in the social life of Cambridge, where he enlarged his already wide circle of acquaintances. He read a great deal, especially in John Stuart Mill, who later became a friend. At a meeting of the British Association in Aberdeen, just a year after his accident, he attracted considerable attention by delivering a paper on The Social and Economic Influence of the New Gold.

In the following year, 1860, he made the first of three unsuccessful attempts to stand for Parliament, but continued to debate public issues with undimmed enthusaism. In 1863, the publication of his popular manual on political economy was well received, and he was appointed to the chair of political economy at Cambridge University. In 1865, on his fourth attempt, he was elected to the House of Commons as the Liberal candidate from Brighton. He was thirty-two.

In the fall of the following year, he was engaged to Millicent Garrett, whom he married in the spring of 1867. With an intellect and character equal to his, she entered fully into her husband's career. He called her "a helpmate whose political judgement was much less frequently at fault than my own." They were joint authors of a book of lectures and essays. In 1924, forty years after Fawcett's death, she was created a Dame of the British Empire in recognition of her work on behalf of women's suffrage.

Throughout his political life, Fawcett defended the rights of the underprivileged against special interest groups. He opposed religious tests for university appointments and argued for open competition and promotion by merit in the civil and diplomatic services. He championed compulsory public education, improved working conditions in factories, and the preservation of commons and other open spaces. He so often sprang to the defense of India in Parliament that he became known as "the member from India."

In 1880, Gladstone rewarded his service to the Liberal Party by appointing him Postmaster General. He established the first British parcel post, expanded the postal savings bank, encouraged the use of money orders by low interest rates, and greatly increased the number of women employees. Unhappily, his term of office was all to brief. In 1882, an attack of typhoid fever seriously weakened his constitution. In November of 1884, a cold followed by pneumonia proved fatal. He was only fifty-one.

Fawcett's ideal of public service was broadly based, but his concern for the general welfare included that of his fellow blind. He helped the American-born Francis Campbell to establish the Royal Normal College for the Blind in 1872. He firmly believed that the blind should be equipped to earn their own living, but he opposed "the walling up" of the blind apart from the sighted world. He urged the blind, "Do what you can to act as though you were not blind, be of good courage, and help yourselves." He advised the seeing, "Do not patronize, treat us without reference to our misfortunes, and, above all, help us to be independent."

Thomas Pryor Gore would certainly have endorsed these sentiments. He was born in Webster County, Mississippi in 1870. When he was eight, a playmate accidentally poked out his left eye with a stick. Three years later, after he had taken a job as a page in the state senate, a stray arrow from a crossbow struck out his other eye. His father wanted him to attend the Institute for the Blind, but he refused to be "walled up" and continued his education in the sighted world.

Young Tom Gore displayed an unusual aptitude for mathematics and could work out complicated problems in his head, but, like Fawcett, his passion was debating. At sixteen, he entered a normal school in Walthall, Mississippi. A classmate reported that his speeches were "filled with fire and fury." Every spring, the school was "converted into the United States Senate and was conducted according to the rules of that body." One of Gore's orations was so inflammatory that it "precipitated a dissolution of parliament." Graduating at nineteen, he taught school for two years in order to pay his way through Cumberland University. He was nominated as a candidate for the state legislature, but was forced to withdraw because he was under age.

In 1892, Gore moved to Texas to practice law. In 1896, he was a delegate to the national convention of the Populist Party in St. Louis. He was defeated for a seat in Congress as the Populist candidate from the Sixth District in 1898. Becoming a Democrat, he campaigned for William Jennings Bryan in South Dakota during the presidential election of 1900. In that same year, he married Nina Kay, who was to serve as his eyes for the rest of his life.

In 1901, the Gores moved to Oklahoma, and Tom made political progress. He served on the territorial council for three years, and when the territory became a state in 1907, he was elected Senator for a short term. He was re-elected for full terms in 1909, 1915, and 1931. He served a total of twenty years in the Senate.

Two concerns nearest his heart were rural credit and Indian affairs. Woodrow Wilson appointed him to the Rural Credits Commission, where his head for figures and keen memory stood him in good stead. A Democrat with Populist learnings, he sought fair play for the small farmer and displaced American Indian. One of his proudest moments in the Senate was a successful filibuster against a bill that would have deprived the Osage Indians of oil royalties valued at thirty million dollars.

Gore lived wholly in the sighted world. He made his way through the hurly-burly of politics in a society still close to the frontier. In 1904, he campaigned for Bryan (and sometimes with him) in whistle-stop tours of Illinois, Indiana, Ohio, and New York. Therefore, when he delivered the opening address to a Washington Conference on the Blind in 1914, his approach was hard--headed and unsentimental.

"It is a mistake," "to tell the sightless that their loss is insurmountable or that it is inconsequential. It is neither. The sightless confront a situation and not a theory."

The Senator then went on to state his strong conviction that "The isolation of the sightless child, as a rule, is a misfortune. It is a calamity." Its effect is to "immure him within cloistered walls, segregate him from the men and women with whom he must ultimately live, amongst whom he must fight the battles of life and win the victories of life, or lose the battles and sustain the defeats."

What happens to blind children raised in sheltered segregation? "Seen but occasionally, and then by kindhearted people who come to caress and console, they imagine that the whole wide world is made up of these sympathetic, these ideal creatures, and that when they emerge from the walls of the institution, they will meet these same generous, kindly philanthropists. They are not prepared for the stern shock of battle. They are not equipped, they are not armed for the combat. They have expected a different contest. They are prepared for a different world occupied by a different set of men and women. I say the sighted child reared under these circumstances would inevitably fail."

With passionate pragmatism, Gore insisted, "You've got to learn men and women firsthand. You've got to know them, before you can succeed amongst them, and you cannot learn them in your imagination or your fancy. Much less can you learn them from occasional glimpses which, instead of illuminating, only serve to deceive. . . ."

As a specific practical reform, Gore proposed the adoption of a single "written language" for embossing books for the blind, instead of the confusing variety of raised type then in use, but he returned to his main point in his conclusion. "The best service that you can render the blind is to help them to help themselves. Let that be your motto! . . . Let that be your purpose! Let that be your object!"

During his last years in the Senate, Gore had a blind colleague in Thomas David Schall. Like Gore, Schall came from a rural background. Born in Michigan in 1877, he moved with his family to Minnesota while still a boy. By working his way, he managed to graduate from the state university with a B.A. in 1902, when he was twenty-five. He married Margaret Huntley and took his law degree at St. Paul two years later. He spent three years building up a law practice before a freak accident with an electric cigar lighter cost him his eyesight in 1907.

Thanks to his wife and his native determination, he resumed the practice of law. Although she had three children, Margaret Schall became both her husband's eyes and his secretary. They worked together so successfully that, in 1914, Tom Schall was nominated as the Progressive candidate for the House of Representatives from the Tenth District.

He faced an uphill campaign "without organization, fame, newspaper support, or money, and with only his loyal and brilliant wife as adviser and guide." Unable to hire halls, he addressed crowds at crossroads and on street corners. He had one great asset. Theodore Roosevelt said, "I believe in Tom Schall with all my heart!" Far more important, Tom Schall believed in himself.

There is more than a hint of ego in a letter to voters that sets forth his qualifications. Pointing out that "Even Jesus, when doing the greatest things for mankind, had to enlist the help of men," he boasted that, despite his blindness, "I can still take care of the interests of my clients against the best legal minds of Minnesota or any other state."

Schall proclaimed, "The heart's the source of power. Men are great as their hearts are great, as their privations, their trials, their patience, their experience of suffering is great. Not in reveling palaces or pillared halls are the deepest emotions felt, grandest conceptions born, or most vital truths discovered, but from Sinai's slopes, the felon's cell at Bedford, from the chamber of blindness in London." He was thus inviting comparison with Moses, Bunyan, and Milton but his next argument had less rhetoric and more reason.

The blind man, he said, "lives through his mind, and like a used key, it must grow brighter. All his other senses are sharpened, and through concentration, all other things being equal, he must excel. True, he doesn't make as good a politician, but he ought to make a better representative of the people in Congress. For the blind man can't go about calling you all by name, Pete and Jim and Jack, slapping you on the back and advising you to get busy and urge your friends to vote for him, but he can, in the committee room or on the floor of Congress, advocate your cause, which is far more essential to your welfare."

Schall made a positive virtue of his blindness. The blind man's "interests are concentrated, while those of the seeing man are diffused by the passing show, because of the very fact that he can see. The minds that have accomplished the most in this world have been most capable of concentration. The blind man's interest in the glitter and show of things is gone. His pleasure and recreation are narrowed down to the product of his brain. His wants physically are few. Money for the blind man, outside of the actual comforts of life, is useless. His great desire is to win the praise of the seeing world. His only ambition is to serve mankind and to leave a name that his children may honor."

Using arguments like these, Tom Schall never lost an election. He served five consecutive terms in the House before going on to the Senate, where he died at the age of fifty-eight in 1935.

Ian Fraser, the last of our four blind lawmakers, was the only one to survive to the present. Born in South Africa in 1897, he came from a well-connected British family. At ten, he was sent "home" for a proper education at Marlborough and the Royal Military College at Sandhurst. Shortly after graduation, he went to France to serve as an infantry subaltern in the Great War. In July, 1916, at the age of eighteen, he was blinded by a German bullet.

Fraser's autobiography, Whereas I Was Blind describes his first reaction to blindness. Rebelliously, he refused to accept it as a reality. A cousin read aloud to him a biography of Fawcett, but it had no effect. Then he had a visit from "a girl who wore the smoothest and most beautiful kid gloves that I have ever felt." She was Irene Mace, an assistant to Sir Arthur Pearson, the founder and chairman of St. Dunstan's Hostel for Blinded Souldiers and Sailors. She carried a letter from Sir Arthur, who had himself gone blind in later life. He invited young Captain Fraser to come to St. Dunstan's, where some two hundred blind veterans were now in various stages of rehabilitation. Smitten by the charms of the message bearer, he accepted.

Fraser made rapid progress at St. Dunstan's. Like Fawcett, he craved physical, as well as mental activity and soon recovered many athletic skills. With Irene, to whom he became engaged, he bicycled to St. Regent's Park Lake every morning and rowed for twenty minutes, while she took the rudder. If no tandem were available, they rode separate bicycles side by side. He kept one hand on her arm and steered with the other. Later, he took to working out in a gym on the rowing machine, chest weights, and punching bag and finishing with a swim in the pool.

He had been at home on horseback since boyhood, and he took up riding again at his cousin's country place. At first, he submitted to the humiliating precaution of having his horse on a lead, but he soon found that, "A horse, like a man, cannot serve two masters." He made out better independently with his companion's voice as a guide. He would some day enjoy rides in the Rockies, Australia, and New Zealand, as well as his native South Africa.

When Sir Arthur asked him to join the staff at St. Dunstan's, Fraser did so and soon proved his exceptional vision, initiative, and administrative ability. He had a mechanical bent, and as early as 1919, he persuaded gramophone companies to experiment with long playing records, in order to make "talking books." At his suggestion, the National Institute for the Blind reduced the size of Braille type with no loss in legibility and a considerable gain in economy. As an important addition to St. Dunstan's vocational rehabilitation, he administered a program of "after care." It had become clear that it was not enough to teach a blind man a few manual skills and then cast him adrift. He required continuing guidance to meet the problems encountered in his work, and communication was a two-way street. St. Dunstan's learned as much from its blind workers in the field as it could teach.

Fraser rose to second in command and was the logical choice to succeed Sir Arthur Pearson on the latter's death in 1921. He was twenty-four. He was the husband of a beautiful and intelligent woman and the father of a baby daughter. As chairman of St. Dunstan's, he had found a snug berth for himself, but he was not content to make a career as a professional blind man. He wrote, "I had already decided before Sir Arthur Pearson died that I must seek a wider outlet than any job at St. Dunstan's might afford and had started to interest myself in politics."

His first campaign was for a seat in the London County Council. In this and later contests, he was careful not to appeal for sympathy as a blind man. The best way to turn his handicap to his advantage was to show that he had overcome it. Although he was a Conservative seeking office in the traditionally Liberal district of North St. Pancras, he won the election and served on the council from 1922 to 1925. In 1924, he was elected to a seat in Commons and, with two brief absences, served continuously until 1958.

He was created a Commander of the British Empire in 1922, a knight, in 1934, and a life peer as Baron of Lonsdale in 1958. He served many years as a governor of the British Broadcasting Corporation and president of the British Legion. He was also appointed the director of several private companies. Here, it is worth noting that Fawcett resigned his directorship of a mining company to avoid conflict of interest when he was elected to Commons. Fraser saw no conflict of interest in his directorships. On the contrary, he felt they enabled him to represent another important segment of the British community.

In Commons, he sponsored several pieces of legislation on behalf of the blind. One enabled blind persons to vote with a companion in the privacy of the polling booth, instead of proclaiming their choices publicly to an official. Another freed the blind owners of radios from the annual licensing charges of the B.B.C. However, his concerns were far from parochial, and he himself felt that one of his most important services was as a member of the Air Committee, which had the vision to develop and strengthen the R.A.F. as a means of military defense.

Fraser's part in the development of talking books was a major contribution to his fellow blind. His experience with ham radio and mechanics gave him a grasp of the technical problems to be overcome, and he spent considerable time in St. Dunstan's laboratory with the professional engineer. The result was a record with two hundred grooves per inch, turning at twenty-four revolutions per minute, and capable of twenty-five minutes of recording on each side. In 1934, the first talking books were recorded in England, and if Fraser cannot be credited with the actual invention, he was nevertheless an essential catalyst in the process that brought them into being.

He was a keen observer of the problems of blindness, and he gave his fellow blind much sound practical advice. "In every day social intercourse," he wrote, "many blind people suffer a good deal, because they are not at ease themselves and do not put their companions at ease. You must remember that, whereas sighted people meet blind people relatively seldom, you are meeting sighted people all the time. The technique for handling them, therefore, is more likely to be understood by you."

He believed that it was far harder for a blind person to find employment than to perform in his job once employed. He needs understanding help to find suitable work, but, once established, he can compete successfully with sighted workers. The higher he rises on the professional ladder, the less of a handicap his blindness becomes. Blindness would be an insuperable obstacle for a postman. It was a minor problem for Fawcett as Postmaster General. A locomotive engineer must see the track. The director of a railroad need not. What he requires is not sight, but vision and a quick incisive mind capable of making decisions. But Fraser insisted that the blind, like the sighted, should be rated on their qualities of mind. To employ an unqualified blind person would be a disservice both to the blind person and the employer.

As lawmakers and politicians, Fawcett, Gore, Schall, and Fraser would doubtless have disagreed on many questions, but they exhibit considerable agreement in their attitude toward blindness. They all believed that the blind should not be separated from the sighted world, but incorporated into it in every way possible. The blind need help, but only in order to help themselves. Too much helpfulness leads to helplessness. Blind people must not be protected out of their freedom.

At the same time, they all felt that the blind must assume a full share of responsibility in adjusting to the sighted world. They could not wait for it to come to them. They must go to it and go more than half way, if necessary.

Perhaps most of all, they would have endorsed Fawcett's favorite quotation from Henry V: "There is some soul of goodness in things evil would men observingly distill it out." They did not minimize the evil of blindness, but they insisted that it did not destroy or even diminish the quality of their minds. Indeed, in some ways, it enhanced them by developing their memories and powers of concentration. What they asked of the sighted world and demanded of themselves was both the freedom and responsibility of exercising their mental powers to the fullest. They were not humble men, and one suspects that their pride may have made them occasionally difficult to get along with, but it gave them the self-confidence they needed to overcome the challenge of competing in a sighted world.

Editor's Note: Whether it be true or not, there is a common impression, both among workers for the blind and public officials that blind people comprise a rather high percentage of successful physically handicapped politicians. A member of the Publications Board advanced the hypothesis that this was in part because they do not have the communication handicap of the deaf, the intellectual handicap of the retarded or the impediment to equipoise of the emotionally disturbed. Added to this was the hypothesis that the constrictions of blindness without loss of mother wit fostered a skill which can be one of the politician's most valuable assets: persuasiveness with language and logic. However, this in mind, the Board asked Mr. Peter Putnam to review the careers of certain outstanding lawgivers with a view to seeing whether or not they shared characteristics in common.

Subsequent to the preparation of this article Lord Fraser died on December 19, 1974. A few hours before his death he had been sworn in as a member of the Privy Council of Great Britain in the presence of Queen Elizabeth II.

EVERGREEN--November 11, 1920

Edith Burrell Harrison[*]

Tall poplars dark against a sunset sky,
Quaint posies crowding each box-bordered bed.
A russet oak-grove shimmering through mist,
Broad spaces, friendly stars far overhead,

The play of sunlight on a copper beech,
Steps winding downward to a silver brook--
Season on season, hour on changing hour
Nature a-riot everywhere you look.

. . . .

These beauties any passer-by may see,
But they who dwell here know a deeper love:
To them Nature reveals her mystery,
Her more elusive charm, below, above.

Swift fleeting fragrance--lilac, cherry, rose,
Box--sun-warmed--honeysuckle, new-mown hay,
The smoke of autumn bonfires, good earth mold
In woodsy places, dry leaves blown away.

Familiar sounds--the robin's reveille,
Crows cawing in the oak grove, wind in trees,
Brooks quiet rippling, mocking birds in spring,
Snow crunching under foot, soft hum of bees.

The feel of clear night air, mist on one's face,
The kindly warmth of sunshine, cooling rain,
Bluff boisterous wind, spurring one on and on
Uphill and down, and then back home again.

. . . .

These revelations come to heal and bless,
And others of the spirit, hardly won;
The great Earth Mother gives to those who seek
Courage and faith and strength to carry on.

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[*] Mrs. Harrison was a rehabilitation aid in the War Blind Program of World War I at Evergreen. There she met and married Philip M. Harrison, who became Executive Secretary of the Pennsylvania Association for the Blind and was a lifetime national leader in work for the blind.

BASIC LEGAL ASPECTS

OF

PLANNING

FOR

DEAF-BLIND PERSONS

Prepared for "1980 IS NOW"

Frank Laski
April 1, 1974

The purpose of this paper is to place into perspective recent developments in the law which affect handicapped persons and explore how the law may influence planning for the Deaf-Blind.

After a few brief notes on the role of law in the planning process, a suggested statement of rights of Deaf-Blind persons will be presented. Recent legal action concerning education, habilitation and treatment will be summarized to illustrate legal principles of due process and equal protection as applied to handicapped persons. Finally, the elements and characteristics of a sound legal framework for planned programs for the Deaf-Blind will be explored.

Serious long range planning for the social welfare and individual well being of a specific population of handicapped persons has not been undertaken often in the United States. In most state and federal programs, despite claims to the contrary, planning for future client needs takes a back seat to meeting current operational priorities. The planning that does take place, with few exceptions, is organized around and focuses on the goals, objectives and activities of discrete service systems rather than on the future needs of a particular population to be served. As a result, plans tend to focus on incremental changes in existing health, education, rehabilitation, employment, and income maintenance systems, highlight and potential of domain expansion within these systems and ignore the interface among service delivery systems, and the possibility of developing completely new systems for persons with complex and varying needs throughout life.

Even more rare in the planning context is the consideration of the law as it affects a specific population of handicapped persons. The idea of planning for legal change in concert with planning for program change has been overlooked; much to the detriment of planners, legislators and handicapped persons themselves. The dynamic interrelationship between law and program planning has been underestimated.

Traditionally, the law has been looked upon as simply a repository of social policy reflecting an amalgam of public attitudes about the handicapped-attitudes which range from concern, compassion, and some sense of community acceptance to pity, isolation and rejection. Since statutes and rules of law are not discarded or modified as readily as scientific and social theories, there is a belief that the law lags behind by necessity, its confusions and contradictions an appropriate reflection of fluctuating social norms. From this reasoning it would then follow that the legal framework governing and regulating public programs for the Deaf-Blind or other handicapped persons, is a matter for lawyers and legislators to take up after plans and programs are developed.

This view of the law as a passive receptacle and implementation mechanism may have some historical validity; however, it should be summarily rejected as a guide for planning. While it is true that effective legal change requires changing public attitudes and political consensus, these factors also attend to successful program planning and development. A truly comprehensive planning effort is one that takes into account the pervasive and active interplay between the law and current and planned programs. On one hand, the planning process can synthesize experience, practices, research, and trends in a number of specialized fields to bring about new understandings of the Deaf-Blind population which in turn can lead to social and political action and program advances on behalf of the target group. On the other hand, it is the law which influences and determines the extent to which Deaf-Blind and other handicapped persons benefit from new understandings, and program advances. It is not simply that legal action in the legislative, administrative and judicial arenas continuously impacts upon the lives of all handicapped citizens, but that a viable legal framework is essential to the successful implementation of new approaches to programs for Deaf-Blind and other handicapped persons.

It should be recognized that when we speak of the law in the context of planning for handicapped persons, we are not exclusively concerned with legislation governing programs for the handicapped or the case law which specifically pertains to deaf persons, blind persons or other handicapped persons. We are concerned about all aspects of the legal process which affect handicapped persons, including laws which regulate or fail to regulate private relationships of handicapped persons (e.g. private contracts); laws which govern accountability and liability of service providers and caretakers; laws which govern domestic relationships; laws which subject persons to governmental processes, criminal or civil; laws which affect personal rights such as right to privacy, right to travel, right to association and religious liberty, and laws which define public responsibilities in generic programs such as education, rehabilitation, employment, transportation, medical care, housing, and exonomic security. Moreover, it is important to realize that legal developments having significant impact on handicapped persons, may occur without any reference to the handicapped. For example, a Supreme Court decision on public school financing may provide legal theories to facilitate equal access to education for handicapped children. A decision upholding restrictive zoning ordinances may foreclose the development of innovative residential alternatives for handicapped persons. Litigation on affirmative action in racial employment discrimination cases may be applicable to employment discrimination against handicapped persons. On the legislative front, enactment of comprehensive national health insurance or termination of the legal services program would affect handicapped persons to a greater extent than many changes in specialized legislation for the handicapped.

While general legal trends and the legal process in total are of considerable importance to Deaf-Blind and other handicapped persons, specialized laws and legal mechanisms applicable to certain classes of handicapped persons deserve in depth examination. These laws may be divided into two categories:

1. Those laws which provide the legal framework for specialized benefits to classes of handicapped persons and,

2. Those laws and legal rules which single out classes of handicapped persons and impose restrictions on the exercise of many rights and privileges of citizens.

Within the first category, a person defined under law as handicapped may be eligible for residential care, pre-school training, day care, special education, extended rehabilitation services, occupational training, employment preferences, or special welfare benefits.

Within the second category under the law, a handicapped person may be excluded from public schools, disqualified from voting, prohibited from contracting marriage, subject to sterilization, discriminated against in adoption, denied licenses of various kinds, and excluded from public benefit programs.

The question of how classes of handicapped persons are defined and identified under law for both restrictive regulatory purposes and program benefit purposes is itself an important legal issue and one that is particularly salient in the case of multiple handicapped persons such as the Deaf-Blind. Two aspects of this problem are worth noting. Firstly, those legal schemes which fail to acknowledge the existence of multiple handicaps and thus sanction perverse outcomes in services to the handicapped (e.g., specialized programs for the deaf, specialized programs for the blind, specialized programs for the mentally retarded, all of which exclude the blind-retarded person, the deaf-retarded person or the deaf-blind person). Secondly, in the matter of definition, there exists some legal tradition of confusing communicative and sensory disorders with intellectual defects and mental handicaps and consequently applying identical provisions to the blind and deaf as to the retarded and in some instances as to the psychotic person.* This issue and other aspects of how handicapped persons are singled out and under the law will be more fully explored in a review of current legal action and trends relating to the handicapped. However, in order to put both past legal developments and current legal action in perspective, it will be helpful to set down in some detail a statement of the human rights which should be guaranteed under law to all handicapped persons.

Simply stated, the Deaf-Blind person, or any other handicapped person must be assumed to have full human and legal rights and privileges. Prosser states the general legal principle, "The man who is blind or deaf or lame or otherwise physically disabled is entitled to live in the world." Yet, the concept of equality before the law and the standard application of general legal principles assumes a minimum capacity to conform to the law and to invoke legal protection. Deaf-Blind persons will vary in capacity to assert their rights under law and many will be at a disadvantage. For those persons, society must compensate and provide additional protection but must do so consistent with conditions least restrictive to personal liberty.

The most important principle underlying the development and protection of human rights of Deaf-Blind and other handicapped persons is that Deaf-Blind persons are individuals with individual characteristics. Like other persons are individuals with individual characteristics. Like other persons, they differ in their skills and weaknesses. Also, like other persons, they will not remain static but, through life, will regress or undergo growth and development depending upon life experiences. It is a challenge to the law and legal institutions to develop mechanisms which recognize the developmental aspects of disability, take into account the variability of handicapped persons and at the same time formulate general principles which will protect and provide for Deaf-Blind persons as a class.

The protections of the U. S. Constitution and Bill of Rights as extended to all citizens through the due process and equal protection clauses of the Fourteenth Amendment are, when correctly applied, more than adequate to instruct us as to the rights of Deaf-Blind persons or other handicapped persons. However, when our concern centers on a small, vulnerable, politically powerless minority, such as the Deaf-Blind, it is useful for our own guidance and clarity of purpose to articulate as carefully as possible those human rights, entitlements and protections which are to be accorded to Deaf-Blind individuals.

There is a caveat which must accompany a statement of rights. In the last decade we have been exposed to much rights rhetoric. The vocabulary has become common; so familiar that we cease to contemplate the real meaning of human and legal rights, especially in regard to the correlative duties we impose upon ourselves as we espouse rights of others. Many of the rights set forth below can be found in the preambles of legislative enactments, resolutions and executive proclamations concerning handicapped citizens. Yet, rarely are these rights fully incorporated in the goals, objectives and administration of programs which bear most heavily on the lives of the handicapped.

The following seven points are based on a resolution adopted in 1972 by the General Assembly of the United Nations on the rights of mentally retarded

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[*] e.g. According to Blackstone: "A man that is born deaf, dumb, and blind is looked upon by the law as in the same state with an idiot, he being supposed incapable of any understanding." LBl. Comm. 304.

persons. It derives from the work of the International League of Societies for the Mentally Handicapped and a declaration formulated by the League in Jerusalem in 1968. It builds upon the Universal Declaration of Human Rights, the U.N., Declaration of Rights of the Child and the U.N. Declaration on Social Progress and Development. The statement is paraphrased below to make specific reference to Deaf-Blind persons. Each principle could be applied to any or all classes of seriously handicapped persons.

1. The Deaf-Blind person has, the same rights as other human beings.
2. The Deaf-Blind person has a right to proper medical care and therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.*
3. The Deaf-Blind person has a right to economic security and to a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities.
4. Whenever possible, the Deaf-Blind person should live in a family environment and participate in different forms of community life. The family with which he lives should receive assistance. If care in a congregate facility becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.
5. The Deaf-Blind person has a right to a qualified personal guardian when this is required to protect his personal well-being and interests.
6. The Deaf-Blind person has a right to protection from exploitation, abuse and degrading treatment. If subject to criminal processes, he shall have a right to due process of law with full recognition being given to his degree of responsibility.
7. Whenever Deaf-Blind persons are unable, because of the severity of their handicap, to exercise all their rights or it should become necessary to restrict or deny some of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards including a plan for providing least restrictive conditions possible, an independent periodic review of restrictions imposed and right to appeal to higher authorities.

With the above stated principles in mind, let us consider how recent legal action has influenced the development of a legal framework capable of protecting the rights of handicapped persons.

In the last few years in the United States we have become more aware of the influence of legal and civil rights upon the ability of handicapped persons to achieve appropriate status in society. Building upon the experience and struggles of our minorities and disadvantaged, the handicapped and their advocates are now concentrating on enforcement of basic constitutional rights rather than, as in the past, relying on special legislative and administrative gratuities. The thrust of a great deal of the advocacy activity on behalf of the handicapped in the U.S. in the last three years is embodied in the previously stated principle that a handicapped person has the same basic rights as other citizens. It is no accident that this principle clearly corresponds to the 14th Amendment of the U.S. Constitution guaranteeing equal protection under the law. In essence, when we speak of civil rights we are talking about treating people equally. In one of the earliest interpretations of equal protection, the U.S. Supreme Court held that all individuals "shall be treated alike under like circumstances and conditions, both in the privileges conferred and the liabilities imposed." In regard to handicapped persons the principle of equality is much more easily espoused than applied. Our notion of equality must be tempered to accord with Justice Frankfurter's admonition that "there is no greater inequality than equal treatment of unequals." However, today judicial, legislative and executive officers in the United States are grappling with real meaning of equal protection in terms of right to education, training, community living and employment.

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*Special attention must be given to the right to medical care and developmental services from birth and throughout life. Amid reports of practices of withholding life sustaining care to handicapped infants and adults, these particular rights add up to no less than the right to live.

Two areas have received greatest attention from the federal courts in the United States. One is education, which has been recognized as a basic right for handicapped persons, and the other is institutional and community treatment which must conform to constitutional standards.

A brief review of selected cases in "right to education" and "right to treatment" may be helpful to planners and administrators to develop plans which enable Deaf-Blind persons to secure due process and equal protection in all dealings with public agencies and private parties.

Pennsylvania Association for Retarded Children v. Pennsylvania was the first case in which a federal court explicitly recognized the concept of equal access to educational opportunity for handicapped children. This civil rights class action brought by PARC and thirteen mentally retarded children on behalf of all mentally retarded persons excluded from schooling directly challenged Pennsylvania statutes which denied education to mentally retarded deemed uneducable, or unable to profit from school, or to those persons not of a mental age of five or those outside compulsory school age. Expert testimony so overwhelmingly demolished the factual underpinnings of the statutes that a consent decree was negotiated in which Pennsylvania acknowledged its responsibility to provide free public education and training to all children. On May 5, 1972, the three judge federal court approved the consent decree and permanently enjoined Pennsylvania education officials and local school districts from denying or postponing a free public program of education and training to any of the Commonwealth's mentally retarded children. In its order, the court noted:

> . . . all mentally retarded persons are capable of benefiting from a program of education and training; that the greatest number of retarded persons, given such education and training are capable of achieving self-sufficiency, and the remaining few . . . are capable of some degree of self care; . . . whether begun early or not, . . . a mentally retarded person can benefit at any point in his life and development from a program of education and training.

Although PARC counsel set forth the constitutional grounds for the right to education when requesting a three judge panel and again when a school district challenged the jurisdiction of the court, the constitutional issues were left for resolution in a subsequent case, Mills v. Board of Education of District of Columbia. The Mills plaintiffs were classified as brain-damaged, hyperactive, epileptic, mentally retarded, mentally retarded with orthopedic handicap, and on the basis of these labels excluded from District of Columbia educational programs. On behalf of all children who had been excluded or otherwise deprived of access to publically supported education, the plaintiffs challenged their exclusion and the procedures and practices by which District of Columbia education and social service officials denied children public education. Basing its decision on the due process and equal protection clauses of the United States Constitution, the Mills court ordered that:

> No child eligible for a publicly supported education in the District of Columbia public schools shall be excluded from a regular public school assignment by a rule, policy, or practice of the Board of Education of the District of Columbia or its agents unless such child is provided (a) adequate alternative educational services suited to the child's needs, which may include special education or tuition grants, and (b) a constitutionally adequate prior hearing and periodic review of the child's status, progress, and the adequacy of any educational alternative.

On the strength of the constitutional holding, the Mills court put the final nails in the coffin of the concept of uneducability making its ruling applicable regardless of degree of type of exceptionality and regardless of the fiscal impact on the school system. Part of the August 1, 1972 decree reads:

> The District of Columbia shall provide to each child of school age a free and suitable publicly supported education regardless of the degree of the child's mental, physical or emotional disability or impairment. Furthermore, defendants shall not exclude any child resident in the District of Columbia from such publicly supported education on the basis of a claim of insufficient resources.

As in PARC, Mills detailed the due process requirements which must be followed in placement, reassignment, or transfer among educational programs. Parents are entitled to advanced notice of placement and reasons for placement; right to a hearing by an independent hearing officer, including right to legal counsel or other advocate, a record of the hearing, right to inspect records, present evidence, cross examine witnesses, and right to appeal.

Cases patterned upon Mills have been filed in at least 30 states. Favorable decisions have been rendered in Louisiana, New York, Wisconsin and Maryland. Before the close of the year, final action is expected in Tennessee, North Dakota, Colorado and a number of other states.

Some of these cases are based on state constitutional provisions and statutes; however nearly all rely to some extent on the equal protection and due process clauses of the Fourteenth Amendment. The constitutional doctrine has been best explained by Attorney Paul Dimond. He writes:

> First, the unjustified exclusion of any child from all public schooling denies to that child the equal protection of the laws when the state makes the opportunity freely available to other children. Second, the operation of our unfair procedure in the stigmatization by public authority of any person or the denial to him of any public good denies the process due each person under the 14th Amendment. Such a stigmatization and denial is involved in labeling children as exceptional, retarded, or handicapped and placing them in a special class, or excluding them from schooling entirely. These two rights, equal protection and due process merge to form the emerging constitutional right to an education which guarantees to every child a minimally

adequate publicly supported educational opportunity. [24 Hastings L.R. at 1093]

Establishment of a clear right to education has great implications for those who are concerned with improving the capacity of the adult Deaf-Blind person to contribute to society in his work and in his daily life. The courts have rejected distinctions between training and education and have accepted a definition of education which goes beyond the narrow concept of schooling. To wit: "Education is a continuous process of developing life skills needed for the effective coping with developmental tasks and demands as well as with environmental tasks and demands."*

A persuasive case might now be made that reasoning used in equal educational opportunity can logically be applied to vocational training prevocational services and other habilitation services vital to optimal adult functioning.

Like right to education, right to treatment is a shorthand for a merger of rights guaranteed by the due process and equal protection clauses of the Constitution. The Eight Amendment's prohibition of cruel and unusual punishment and the Thirteenth Amendment's guarantee of freedom from involuntary servitude have also been used to bolster the case for the creation of a right to habilitation and treatment.

The right to treatment emerged in cases challenging the confinement of civilly committed mentally ill patients. It was argued that if the need for treatment provides the rationale for confinement than the patient must actually be treated or released. This argument was given some recognition by courts in the District of Columbia, and Massachusetts in the mid sixties, but had little impact on patients or mental health service providers until raised in Wyatt v. Stickney and applied to all mentally ill and mentally retarded persons confined in public institutions in the state of Alabama.

In regard to the mentally ill, Chief Judge Frank Johnson stated that committed patients "unquestionably have a constitutional right to receive such individual treatment as will give each of them a realistic opportunity to be cured or to improve his or her mental condition."

As to the residents of Partlow State School, it was held "the mentally retarded have a constitutional right to receive such individual habilitation as will give each of them a realistic opportunity to lead a more useful and meaningful life and to return to society.

Initially, the court ordered the state to develop a plan for treatment and habilitation. However, further relief was required by Alabama's failure to improve the conditions which expert testimony had shown to be inhumane and devastating to residents--conditions which were characterized by lack of safety, lack of privacy, malnutrition, exploitation of patient labor, solitary confinement, excessive use of restraints, inadequate staffing, lack of individualized programs, deterioration of physical and mental conditions, brutality and patient deaths. Therefore, to rectify these conditions and implement the right to treatment, the Wyatt court not only set down the general parameters of minimum treatment (i.e. a humane psychological and physical environment; a qualified staff in numbers sufficient to administer adequate treatment and individualized treatment plans) but also set forth in detail the minimum constitutional standards for adequate habilitation of the mentally retarded, and adequate treatment of the mentally ill. To monitor implementation and guarantee that residents are afforded constitutional and humane treatment, the court directed the establishment of a human rights committee and retained jurisdiction of the case.

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*Testimony of Ignacy Goldberg, PARC Hearing of August 12, 1971.

The Wyatt court just as Mills faced the funding question head on and indicated that lack of operating funds could not justify withholding habilitation. Chief Judge Johnson stated:

> In the event, though, that the Legislature fails to satisfy its well-defined constitutional obligation and the Mental Health Board, because of lack of funding or any other legally insufficient reason, fails to implement fully the standards herein ordered, it will be necessary for the Court to take affirmative steps including appointing a master, to ensure that proper funding is realized and that adequate habilitation is available for the mentally retarded of Alabama.

The existence of a judicially enforceable constitutional right to treatment and the approach to implementation taken by Judge Johnson in Wyatt was rejected by another federal court in Burham v. Department of Public Health of Georgia. Wyatt and Burham have been joined on appeal before the Fifth Circuit. In Welsch v. Likens, recently decided in the U.S. District Court for Minnesota, Judge Earl Larson fully accepted the reasoning of Wyatt and found a right to treatment under the due process clause of the Fourteenth Amendment and under the Minnesota statutes. In other cases, federal courts in New York and Massachusetts, while avoiding the question of the nature of a constitutional right to treatment, have granted relief in line with minimum enforceable standards. In these subsequent cases on institutional treatment rights secured and relief provided has applied to those persons admitted voluntarily as well as those committed. In addition to the aforementioned cases, mental health and retardation administrators are defendants in right to treatment suits in Nebraska, Illinois, North and South Carolina, Missouri and Tennessee.

While the right to treatment cases have arisen in the context of grossly substandard institutions for mentally disabled persons, the principles may be applied to any residential setting which restricts the personal liberty of residents. There is a growing body of law, in juvenile cases, adult corrections cases and other areas, recognizing a constitutional right to treatment for persons confined in various settings under State Authority. It is clear that this right entails more than caretakers and service providers doing the best they can within the limits of existing resources. As Judge Larson noted in Welsch:

> . . . good faith is not at issue here. It does not suffice, therefore, to show that conditions have been upgraded, that the situation will continue to improve in the future, and that even more achievements would be forthcoming. . . . It is the Court's duty, under the Constitution, to assure that every resident . . . receives at least minimally adequate care and treatment consonant with the full and true meaning of the due process clause.

Legal action on behalf of handicapped persons in the areas of education and treatment exemplify a broad trend toward litigation and judicial intervention relating to various service systems. Physically handicapped persons have secured judicial enforcement of their right to access to public transportation and public buildings. Favorable decisions have been rendered in regard to entitlement to minimum wage and classification and placement procedures for specialized services. Litigation is being brought on employment discrimination and rights to community services.

Litigation and legal developments noted have caused reverberations outside the courtroom and have influenced state and federal policy makers. Judicial action on right to education, and treatment has caught the attention of state legislators as evidenced by a recent resolution of the National Legislative Conference to develop model legislation relating to the needs of developmentally disabled persons, taking into account the role of institutions, education and community programs. More concrete examples are the hundreds of bills promoting education of the handicapped enacted into law by state legislatures during the last three years. Tennessee and Massachusetts have enacted comprehensive laws codifying many of the principles and rights enunciated in PARC and Mills. Implementation in North Dakota, Michigan, and Wisconsin is proceeding with an assist from potential or pending litigation. In treatment, Massachusetts is implementing its completely revised mental health; mental retardation code, while at the same time under court order to provide habilitation to institutionalized mentally retarded. In Ohio and Florida comprehensive codes incorporating a statutory right to treatment have been drafted and are before the legislature. An anti-peonage statute has been enacted in Indiana.

At the federal level the influence of the legal rights movement is reflected in both Congressional and Executive action. The Rehabilitation Act of 1973 is an important step in the movement toward the concept of habilitation and rehabilitation as an entitlement. The legislative history of the act shows a clear concern for client advocacy and client participation in rehabilitation plans. Title V is replete with new tools for advocates to assert rights to employment and access to transportation and buildings. Amendments to the Civil Rights Act of 1964 to specifically protect handicapped persons from all types of discrimination has been urged by Congressional leaders, and a "Bill of Rights for the Retarded," incorporating the standards approach of Wyatt, has broad-based sponsorship in the United States Senate. H.R. 70, S. 6 and other pending federal education legislation aimed at assisting states to implement fully the right to education mandate can be viewed in part as a response to federal court action.

On the executive side, the President's concern for providing the handicapped ready access to the legal system and his directive to the Justice Department to take action to protect the rights of retarded persons led to Justice Department participation as friend of the court in right to treatment cases (NYARC v. Rockefeller) and right to education. Most recently, the Civil Rights Division filed suit on behalf of the United States challenging as unconstitutional the practices of an institution for the handicapped in Maryland.

In addition, a number of Health, Education and Welfare agencies are supporting advocacy efforts (including legal advocacy) on behalf of the handicapped without the ambivalence that has characterized administration support of advocacy on behalf of other disadvantaged groups.

The spread of legal action and the legislative and administrative reaction noted above have led some enthusiastic observers to speak of a rights revolution. Whether it is a revolution, remains to be seen. Yet this much is certain, the decisions to date when considered with other major trends such as increased client militancy, increased provider accountability, decentralization of services, and increased community acceptance of handicapped persons, have the potential to bring about substantial changes in all existing and planned programs that serve or are intended to serve the handicapped. Whether the program changes brought about by legal action will actually accrue to the benefit of the handicapped will depend largely on the ability of planners to weigh the programatic implications of legal action and translate judicial decisions into program advances.

A careful examination of the direct program implications of the various legal actions is of considerable importance for comprehensive planning. However, perhaps the major future impact of litigation is grounded in the fact that all the decisions and decrees in one way or another accept, promote and give public policy status to two theoretical constructs which have emerged recently to undergird new approaches to service delivery. These constructs, the developmental model of disability and the principle of normalization, have been most widely used in the context of mental retardation and developmental disabilities but are applicable to all disabilities. Jacobus ten Broek set forth similar concepts of integration for blind and other physically handicapped persons, and Richard Allen has given some thought to an across the board legal application of normalization to all handicapped persons. The developmental model of disability views all handicapped persons as capable of growth, learning and development. Human development and behavior are products of interaction between the individual and his environment rather than attributes of a specific impairment. The model emphasizes the potential to alter development and incorporates positive actions to accomplish developmental goals. Consequently, it provides for the accountability of professionals and others for developmental failures brought about by lack of environmental conditions. While the developmental model contemplates intervention to modify both behavior and environment, the normalization principle guides that intervention and requires that the handicapped person have an environment and life-style that is as close to normal as possible. The normalization principle has been translated for use in educational services, residential services, transportation, social services and other human services.

The developmental model and normalization principle provide a sound basis for the development of legal theories to protect rights of Deaf-Blind and other handicapped persons. The developmental model of disability not only undercuts many of the assumptions behind existing statutes and common law restricting handicapped persons, but it provides a great part of the rationale for judicially mandated affirmative action to modify conditions detrimental to handicapped persons. The normalization principle provides the courts with a useful gauge to develop standards of fairness and due process and assess accountability in relation to the extent to which practices isolate handicapped persons. In this regard, the normalization principle links up with a congruent legal principle of right to least restrictive alternative. Generally stated, it holds that where governmental activity leads to regulation adversely affecting constitutionally-protected activities or constitutionally preferred groups, there is an obligation to explore and employ alternatives which can accomplish governmental purposes through means least restrictive to personal liberties. Many lawyers believe that this legal principle can be developed to frame our approach to challenging discrimination against the handicapped in whatever form it may take and in whatever setting it may occur. One may speculate, however, that in this area the law will not venture ahead of practice and that strength of the legal principle of least restrictive alternatives rests largely on the consistent articulation and application of the development model and normalization principle to all services for all handicapped persons, and the actual development of a range of alternatives for handicapped persons. Thus, it is imperative as legal action continues and becomes more complex to consider in advance what these legal propositions mean in terms of programs for Deaf-Blind persons with particular attention to the world of work, sheltered work, economic security, domestic relationships and other important areas of adult functioning.

GENETIC COUNSELING AND BLINDING DISORDERS

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Awareness of genetic eye diseases is increasing due in part to an increased emphasis on the role of heredity in human disease and through improved methods of detection by medical personnel. Equally important, however, is the progress being made in diagnosis and treatment of nongenetic ocular disease. Glaucoma and retinal detachments, once considered to lead to inevitable blindness, can now be successfully treated in most instances. Therapy of retinal neovascularization and vitreous hemorrhage sometimes restores useful vision, at least temporarily, in disorders which, until very recently, were considered incurable.

In spite of the increasing prominence of genetic factors in the etiology of ocular disease, the treatment of visual morbidity is still largely oriented towards medical or surgical therapy after the onset of symptoms. While this approach may be justified in selected diseases such as cataracts or strabismus, it is certainly a classic example of "too little too late" in the case of many degenerative disorders in which irreparable damage occurs. Considerable attention has recently been focused on the importance of prevention in traumatic blindness. However, relatively little emphasis has been given to the prevention of genetic blinding disorders with the result that affected families and patients frequently remain unaware of possible alternatives to the physical and financial burdens of blindness. Ophthalmologists (as well as other physicians) tend to consider heritable disorders as forms of "chronic diseases" having little more than curiosity value with virtually no prospect for effective therapy. While it is true that medical and surgical treatment of genetic diseases often yields disappointing results, we should not ignore other means of reducing the visual morbidity caused by genetic factors. At the present time, prevention of their transmission through genetic counseling remains one of the most effective means.

Personnel employed by agencies and associations for the blind often spend much time with patients and have extensive contact with relatives. Consequently, the emotional rapport may exceed that of the doctor and his patient, and, since counseling and guidance are already part of this relationship, workers among the blind have considerable opportunity and responsibility to ensure that all who can benefit from genetic counseling are advised of its availability.

The primary goal of genetic counseling is to reduce the risk of heritable disease by allowing potential parents to select healthy offspring. This, of course, requires a thorough understanding of basic genetic principles and the manifestations to train genetic counselors, it will hopefully lead to improved counseling and prevention of blinding disorders.

Mechanisms of Inheritance

All heritable aspects of our physical and mental constitutions are determined by constituents of cell nuclei called genes. The determinant material in genes is deoxribonucleic acid (DNA) which forms a long, double stranded, chain-like configurations which, together with an assortment of proteins and other molecules, is microscopically visible as a chromosome. In humans, the number of chromosomes in each cell is 46 (23 pairs) with the exception of the reproductive or germ cells, in which the number is halved. Thus, each parent contributes 23 chromosomes to the fetus which ends up with 46 per cell. Two of these are known as sex chromosomes, which in females are alike (designated X chromosomes), while the male has a single X plus another one known as a Y chromosome. The remaining 44 are called autosomes.

A gene is defined as a segment of DNA that is responsible for the synthesis of a single biochemical product. The "code" for each product is determined by the linear arrangement of four molecules (nucleotide bases) in triplets; i.e., each component (amino acid) in a protein is specified by the order of three of the four base molecules. For a molecule such as hemoglobin with 141 amino acids, a total of 423 precisely sequenced bases is required for its proper synthesis. One form of genetic mutation, often called a point mutation, results from the alteration of a single base. An example of this mechanism is sickle cell (SS) anemia, a usually fatal form of blood disease in which the associated retinopathy may lead to retinal detachment and blindness. Normally, glutamic acid is located in the number six position of the beta chain of hemoglobin. In SS disease, however, valine is substituted as a result of a change in one member of the triplet code of bases. All the tragic consequences of sickle cell anemia result from this seemingly minor change--truly a molecular disease! Since we have many thousands of genes, each with many bases, it is remarkable that not more of us are afflicted with deleterious mutations.

Fortunately dividing cells usually reproduce their chromosome complement accurately and, as a result, subsequent generations of individuals (and cells) receive precise copies of the parental chromosomes. Rare errors in this process, however, lead to derangements in chromosomes, usually with disastrous clinical consequences. The best known example of this form of genetic disease is mongolism or Down's syndrome, in which there are 47 instead of 46 chromosomes. In other cases, only a portion of one chromosome is duplicated or lost while in still others novel combinations are present. Since each chromosome carries thousands of genes, microscopically visible alterations involve huge amounts of DNA and, therefore, are usually associated with widespread clinical abnormalities. None with purely ocular defects are known.

Most point mutations probably do not by themselves produce clinical disease. Instead they may simply increase the individual's susceptibility to environmental influences. In individuals with the genes for galactosemia, for example, cataracts do not form if galactose is kept from the diet. In other cases, mutiple mutations must be present before clinical abnormalities occur. Strabismus and refractive errors are probably determined by this mechanism, known as multifactorial inheritance.

A genetic defect may be defined as any disorder or anomaly caused by an abnormality in the genetic material. In many cases, of course, such errors in the genes and chromosomes are inherited from the parents; in many others, however, genetic disorders arise *de novo* through new mutations. Thus, transmission from one generation to the next is evidence for a genetic etiology, but not required for confirmation.

Two additional terms, "congenital" and "hereditary" require definition since they are often erroneously substituted for each other. Congenital means simply "present at birth" and does not imply a genetic etiology. The distinction is important because many disorders present at birth are not genetic in etiology (rubella cataracts, traumatic corneal abrasions, toxoplasmic retinitis, etc.) nor are hereditary disorders always present at birth (galactosemic cataracts, retinitis pigmentosa, Best's disease, corneal dystrophies, and dislocated lenses). Technically, of course, the defect in the genetic material is often transmitted at conception, but the *clinical* manifestations may not appear for many years.

Nature of Information Sought in Counseling

The type of information requested of the counselor may vary. Sometimes adoption agencies wish to know the racial background of a child in order to facilitate placement. Occasionally, probability estimates are needed to aid in the settlement of paternity disputes. Usually, however, an individual or family simply requests information regarding the probability that a certain disease or malformation will appear among future offspring. For example, a married nulliparous female may want to know, before starting her own family, whether there is a significant risk that her male offspring will have sex-linked albinism since her father and brother are visually handicapped by this disease.

Rarely, the patient who desires counseling (referred to here as the consultant) wants to know his personal risk of developing a genetic disease. Sometimes attempts are made to find out indirectly by inquiring about risks in offspring or other relatives. A 21-year old unmarried college male inquired of a genetic counselor whether he should have any children since his mother and aunt died of polycystic kidney disease. It was not until the second interview that the patient revealed his concern about the wisdom of investing time and effort in graduate school since he might develop this incapacitating illness during early adult life.

Data Needed for Determination of Risk

The accuracy of genetic risk calculations is dependent upon correct diagnosis of the disorder in question, size and accuracy of the pedigree, availability of prior information about the disease, precision of prenatal diagnostic techniques, and, in some cases, a knowledge of environmental factors that can mimic or modify heritable disorders.

An accurate diagnosis is essential in genetic counseling since recurrence risks may vary widely for different diseases which superficially appear identical. For example, a patient with a combination of dislocated lenses, skeletal dysmorphism and cardiovascular disease may have either homocystinuria or the Marfan syndrome. If the syndrome is caused by a deficiency of the enzyme cystathionine synthase, the patient can be assured that his offspring will all be normal since he has homocystinuria, an autosomal recessive disease. However, if he has the Marfan syndrome, an autosomal dominant, he can expect that 50% of his children will inherit the same disease. Often, however, specific biochemical tests are not available and the diagnosis must rest upon clinical acumen alone. To complicate matters further, certain characteristics of genetic diseases such as heterogeneity (one syndrome, several etiologies), pleiotropism (one etiology, multiple manifestations), lack of penetrance (mutation present, but no disease detectable), and variable expressivity (variation in disease manifestations) often add uncertainty to the diagnosis. The breadth of medical knowledge and expertise required for genetic counseling determines the need for physicians to share in the counseling process.

The degree of confidence placed in risk estimates is largely dependent upon the amount of information available from the pedigree. Since genealogical data provide the reference points for all genetic counseling, I usually advise patients to bring any available family and medical data to the first interview. Sometimes the family history is non-existent as, for example, in the case of adopted children, but for meaningful risk determinations, information on at least three generations is required. The need for this minimum is apparent for multifactorial disorders, congenital malformations, and chromosomal aberrations (vide infra), but even for some disorders caused by single gene mutations, complete pedigrees are necessary to decide between alternate modes of inheritance or to exclude new mutations.

It is important to obtain complete data on the health of all family members. Since many genetic disorders have been described relatively recently, it is necessary to inquire about specific signs and symptoms rather than general diagnosis alone. Questions regarding the presence of "similar diseases or problems" often yield incomplete and inaccurate information. For example, a 56-year old female telephoned to inquire about the risk of "retinitis pigmentosa" among future grandchildren since this diagnosis had been made in both her and her mother nearly thirty years ago. However, when examined, it was found that three members of this pedigree had fundus flavimaculatus, a retinal disorder which, until recently, was considered by many ophthalmologists to be an unusual form of retinitis pigmentosa.

Are of disease onset or of death can sometimes provide useful diagnostic clues. For every sibship, it is necessary to emphasize that information is desired on each pregnancy since parents frequently assume that data is needed on surviving members only. Whenever possible, medical records from other physicians, hospitals, or other institutions should be consulted since they may contain the results of diagnostic studies or autopsies of other pedigree members.

Consanguinity may be an important clue to the etiology of disorders where no clear mode of inheritance is certain. Detection of first cousin marriages, the most frequent consanguineous mating encountered in our society, requires data on at least three generations while more remote relationships of possibility equal significance require proportionately more pedigree data. When couples are unable to provide sufficient data to establish the exact degree of relationship, it is sometimes possible to utilize indirect clues. Since ethnic, religious, and geographical isolation of some populations are responsible for the majority of inbreeding in this country, common origins can often be used as suggestive evidence of consangunity.

Parental ages at conception of affected individuals should be determined. Advanced maternal age increases the risk of certain chromosomal aberrations, while advanced paternal age is known to carry with it a higher risk of new mutations.

It is frequently useful, although not always necessary, to schedule additional interviews since the consultant may later recall other vital information or will obtain additional data after consulting other members of the family. He may wish to examine other sources of information such as genealogical publications or family archives. In the interim, the counselor can frequently obtain useful data by performing diagnostic studies on other family members or by requesting the results of studies done elsewhere. As illustrated previously, an additional benefit of multiple interviews is an improvement in the patient-counselor relationship that may encourage the consultant to verbalize related concerns.

Following diagnosis of the disorder, and after the family history and pedigree are assembled, the next step is to determine whether the disease is caused by a single gene mutation, a chromosomal aberration, or by interactions of multiple factors. Since the magnitude of the recurrence risk and the methods of determination vary for each of these major etiological categories, it will be useful to consider them separately.

Counseling in Major Forms of Genetic Disease

I. Single Gene Mutations

More than 100 years ago, an Austrian monk, Gregor Mendel, first delineated the inheritance patterns of single gene or point mutations. Mendel's observations in the garden pea were later found to have general validity in other organisms including humans. Consequently, characteristics resulting from this type of genetic defect are often referred to as mendelizing traits. Incidentally, the first inherited human defect found to follow Mendel's laws was an ocular disease, color blindness, whose sex-linked (sometimes called X-linked since the mutation is located on the X chromosome) transmission pattern was described by Nasse in 1820.

Since the recurrence of mendelizing disorders can be predicted from the inheritance patterns, it is obvious why accurate pedigrees are prerequisites to counseling. In cases where genealogical data are incomplete, it may be possible to calculate risks from published pedigrees of the same disease. It must be remembered, however, that certain clinical syndromes such as congenital cataracts, retinitis pigmentosa, and macular disorders may have several modes of inheritance, and information from other pedigrees may not be appropriate for a given family.

Occasionally, exhaustive pedigree research fails to reveal more than one individual affected with a presumed genetic disorder. In such cases, it is necessary to exclude non-genetic factors which may produce phenocopies, i.e., non-genetic disease which mimic heritable syndromes. Other causes for sporadic cases such as new mutations and illegitimacy should also be investigated.

A. Autosomal Dominant Inheritance

Disorders such as aniridia, Best's macular dystrophy and granular dystrophy of the cornea are caused by a single mutant gene located on an autosome, i.e., non-sex chromosome. Both sexes are therefore affected with equal frequency. This is known as heterozygosity since the gene on the paired (homologous) chromosome is normal. Half of the reproductive cells carry the normal gene and the remainder carry the abnormal one. Thus, offspring of an affected individual have a 50% risk of inheriting the mutant gene, or, alternately, one-half of the offspring of affected individuals will carry the mutation. Individuals inheriting the normal gene will never transmit the defect to future generations.

Not all individuals who inherit the mutation necessarily manifest clinical disease, however, due to lack of expression, i.e., non-penetrance of the gene. The prevalence of disease among offspring of affected persons may thus be less than 50%. For example, Dollfus and Auvert (3) estimated a penetrance of 40% for the heritable form of retinoblastoma, a tumor of the retina found among young children. An affected consultant contemplating reproduction could be given a risk figure of 20% (.40 x .50) for the probability of an affected child; however, the same individual should also be warned that one-half of the total offspring will actually inherit the gene and carry the same (20%) risk of having affected children. Clinically normal offspring of affected parents with an autosomal dominant disorder in which penetrance approaches 100% can be assured that the recurrence risk for their children is negligible.

Special problems are encountered whenever the manifestations of a disease are delayed beyond puberty since there may be no certain way of determining the genetic status of the consultant prior to reproduction. This may be encountered, for example, in certain types of macular dystrophies and in retinitis pigmentosa. In such cases, it may be helpful to consult empirical data regarding age of onset of the clinical disease in order to modify the risk calculations (4).

B. Autosomal Recessive Inheritance

Disorders such as Stargardt's macular dystrophy, tyrosinasenegative albinism, and one form of retinitis pigmentosa are caused by two identical mutant genes located on homologous autosomes (i.e., homozygosity). Clinical disease is thus manifest in homozygous individuals, usually conceived through the mating of two heterozygotes. Since the parents carry the mutation in single dose only, they are clinically normal. Even large pedigrees of affected families therefore usually contain no other sibship with the same disease unless considerable inbreeding occurs. When consanguinity is present, one or both parents may also be affected (homozygous) and the pedigree pattern superficially resembles an autosomal dominant pattern (a situation known as pseudodominant inheritance).

For heterozygous parents, the risk for each conception is 25% (regardless of sex). That is, one-fourth of such offspring will be affected by clinical disease. However, two-thirds of the remaining offspring, although clinically normal, will inherit one of the mutant genes from the parents, i.e., will be heterozygous. Both affected individuals and heterozygotes can be assured of normal offspring if the gene is rare and if they do not marry a relative. Such assurance can be given with greater confidence if biochemical studies in their spouses definitely exclude carrier status (this is now possible in at least 46 genetic diseases, including five with important ocular manifestations).

C. Sex-linked Dominant Inheritance

Sex-linked dominant disorders such as vitamin D-resistant ricketts and orodigitofacial dysotosis are rare. In this form of inheritance, a single mutation on an X chromosome is sufficient to cause disease in both sexes. Females are usually affected with a frequency twice as great as males. Since males give their X chromosomes only to female offspring, affected males can be assured of normal male offspring, although all their daughters will be affected. Affected females must be given the probability that one-half of their children, of both sexes, will be affected.

D. Sex-linked Recessive Inheritance

Diseases in males caused by a mutant gene on an X chromosome, such as juvenile retinoschisis, choroideremia and ocular albinism, are known as sex-linked recessive disorders since their effect is repressed by a normal gene on the homologous X chromosome carried by females. The heterozygous female usually does not have functionally significant disease, although careful examination may reveal minor abnormalities such as fundus changes in choroideremia and iris transillumination in ocular albinism.

As in sex-linked dominant disorders, affected males cannot have affected male offspring and since heterozygous females are clinically normal, neither will have affected daughters (assuming no consanguinity). An affected male can therefore be assured (provided the gene is rare and he does not marry a relative) of having clinically normal children, although all of his daughters will be carriers and they could present him with affected grandsons. Parents of affected males have a probability of 50% that each subsequent male offspring will be affected since one of the maternal genes is mutant. One-half of their daughters will be carriers like their mother.

Clinically normal males (with affected male sibs) have no risk of passing the disease on to subsequent generations. Sisters of affected males have a 50% probability of being carriers, and since each of their male offspring has a 50% chance of receiving the defective allele, from his mother, the combined probability that such a female will have an affected male child is 25% (0.50 x 0.50). Of course, if clinical or laboratory examination reveals that the mother is a carrier, or if she has already proven her carrier status by having an affected child, the risk immediately reverts to 50%.

For a female of unknown carrier status (i.e., with no affected sons and in which the presence of the gene cannot be determined by laboratory or clinical examinations), the risk to future male offspring is decreased following the birth of each normal male child. The probability of recurrence also decreases as the number of generations since the last known carrier in her pedigree increases. The explanation is simply that each negative event (lack of affected offspring) decreases the likelihood that the individual in question is a carrier. The general formula for these situations has been developed by Murphy (4) and representative values are presented in Table I. It should be emphasized, however, that regardless of the number of normal sons or the number of generations elapsed since the last known carrier, the birth of an affected child to any female proves her carrier status and the risk of disease for each subsequent male fetus returns to 50%.

The recurrence risks cited here are based upon the known biological behavior of genes and confirmed by studies in large numbers of families. Like small numbers of tosses of a coin, however, the composition of human families may not conform to the predicted average. Therefore, it is important to emphasize in counseling that "chance has no memory," i.e., regardless of the proportion of children already affected, each subsequent conception is a unique event. This should always be explained to consultants since some assume that they have already had their "share" of affected children and, therefore, have less risk of future conceptions.

II. Chromosomal Aberrations

Approximately one in 150-200 newborns carry a detectable chromosomal abnormality and at least 40% of embryos aborted spontaneously during the first trimester have a similar aberration. These may involve either autosomes or sex chromosomes. In most cases, chromosomal abnormalities are non-familial and occur only sporadically. Exceptions to this occur, of course, when one of the parents carries a balanced translation or is himself affected by a chromosomal abnormality. For this reason, chromosome studies should be performed on all parents of children with chromosomal aberrations.

Recurrence risks for parents with chromosomal abnormalities vary according to the sex of the carrier parent and the type of abnormality (Table II). For example, carriers of a 21/21 translocation have a 100% risk of producing a mongol child compared with a male carrier of a D/G translocation who has a low risk (approximately 2%) (5).

In order to calculate risk figures for each type of chromosomal imbalance, it is necessary to first determine the chromosome combinations that are possible in the fetus, and then to compute the proportion of such possibilities that can cause clinical disease. Lethality of certain combinations resulting in spontaneous abortion must always be considered since this in effect increases the risk for each viable offspring, but the existence of lethal types may not be self-evident and can only be determined from the results of large numbers of pregnancies.

Sporadic cases of chromosomal abnormalities in which parental chromosomes are normal require a different approach. The etiology is usually unknown so that accurate counseling is difficult. In some of the best studied syndromes, such as those due to E-trisomy, D-trisomy and 22 trisomy (mongolism), advanced maternal age seems to increase the risk. For example, the risk of trisomy 22 mongolism for any pregnancy among women of all reproductive ages is approximately 1 in 600 (5). The risk increases rather dramatically, however, for women above the age of 35 years (Table III). In addition, the risk of mongolism is increased approximately three-fold following the birth of a child with 22 trisomy. The reasons for this are unknown, although a genetic influence seems likely. A search for simple recessive mutations causing an increased susceptibility to trisomy 22 mongolism, however, failed to reveal such genes (6). Not only is the frequency of mongol sibs greater than would be expected from random expectations alone, but sibships containing a child with mongolism are also more likely to have other chromosomal abnormalities than would be expected from chance occurrence alone.

III. Congenital Malformations Not Caused by Single Gene Mutations

Disorders such as strabismus, glaucoma, and refractive errors which do not follow simple patterns of inheritance and in which no chromosomal abnormality can be identified, cannot be predicted with accuracy and represent difficult problems for the genetic counselor. Often a multifactorial etiology is assumed, but the degree to which the environment and gene mutations interact to produce disease is unknown. For these disorders, it is especially important to pursue every aspect of the family history in order to rule out the possibility that the defect is a subtle expression of a more generalized, simply inherited disorder. If the pedigree and history are extensive enough, it may be possible to estimate the recurrence risk from the distribution of affected individuals. Of course, the possibility always exists that the defect in the family counseled is actually a "new" disorder.

Usually, recurrence risks have to be based on empirical data derived from epidemiological studies. Unfortunately, few such data are available for ocular manifestations, although occasional reports (2, 7) may list these among tabulations of the causes of blindness. Serious consideration should be given to the nationwide collection of epidemiologic and genetic data on ocular malformations in order to monitor trends in incidence and to provide a better data base from which to determine recurrence risks.

Presentation and Interpretation of Data

Genetic counseling differs from conventional therapeutic modalities since its effective utilization, for legal and moral reasons, depends almost entirely upon the initiative and cooperation of the requesting individual or family. The utilization of contraception, reproductive sterilization, or abortion as alternatives to the birth of a genetically defective offspring requires voluntary consent and active participation. Therefore, the counselor is not only responsible for the accuracy of his risk determinations (choosing the "type of therapy"), but he must also be able to effectively interpret and communicate the significance of such data.

Isolated recurrence risk figures have little meaning for most individuals since they have no basis for comparison. The counselor should be prepared to explain the meaning of a 25% or 50% recurrence risk but he should avoid injecting personal prejudices since deepseated moral and emotional considerations may strongly influence the consultant's actions.

It is advisable to place genetic risks into some perspective that will enable the patient or family to evaluate the consequences of alternate courses of action. For example, it has been estimated that 6% of all newborns have a defect or will develop an illness caused by genetic factors (8). Therefore, the recurrence risk of another mongol child due to trisomy 22, except for mothers near the end of their reproductive years, adds only a small additional risk to those already present. This may provide some reassurance to a young mother whose first child has trisomy 22. For most sporadic types of congenital malformations, the recurrence risk is also small, often less than 1%. Many couples with a malformed child have fears of much higher risks.

It is useful also for the counselor to develop his concepts regarding the relative magnitude of genetic risks in order to convey some sense of their proportion to patients. Many patients, following presentation of actual figures, will inquire directly if their risk is "large" or "small." The simple and logical classification of the relative magnitude of recurrence risks in Table IV has been found useful by many patients who had difficulty comprehending absolute figures.

Another important function of the counselor is to provide an explanation of the various alternatives available to high risk couples. These, of course, will vary depending upon the marital and conception status of the patient. Most patients today first seek counseling following the birth of an affected child, but, unfortunately, many still wait the next pregnancy. As advances in diagnostic genetics are disseminated, an increasing number of couples are seeking advice before they begin their family, and occasionally even before marriage, when a strong family history of genetic disease is present. Hopefully, this type of early counseling will increase.

For couples in which the female is not pregnant, there is usually adequate time to obtain the necessary data, calculate the risks, and plan a rational course of action. In this case, the counselor can be most helpful by providing information which allows each couple to decide whether or not they will risk having additional children. Sterilization or contraception are reasonable alternatives for couples who consider the recurrence risk too great.

However, for other couples who decide to risk another conception, and for women already pregnant when counseling is first sought, the counselor should be prepared to offer further assistance such as prenatal diagnosis and, in selected cases, termination of high risk pregnancies. In the past five years, significant advances have been made in pre-natal diagnosis of both metabolic and chromosomal disorders (9). It seems likely that this technique will receive increasing application since the exact diagnosis thus provided eliminates the uncertainty inherent in probabilities. At the present time this preventative approach is the best alternative to postnatal medical and surgical treatment of genetic defects which, at best, only increase longevity but are not curative. Hopefully, continued advances will reduce the need for genetic counseling to situations in which high risk pregnancies are monitored and appropriate therapy instituted before clinical disease is evident.

Summary

The genetic counselor should be able to compute accurate recurrence risks and to explain these to families with genetic disorders. The determination of risk requires an accurate diagnosis, a complete family history and construction of a pedigree with supplementation of published data whenever indicated.

Genetic risks range from less than 5% to 100%. Most diseases due to single gene mutations have a recurrence risk of 25 to 50% in single sibships, but consanguinity, reduced penetrance and sex of the offspring may raise or lower the risk. The majority of chromosomal disorders occur sporadically, but parents should be karyotyped to exclude translocations or similar abnormalities since these increase the probability that future offspring will also be abnormal. The recurrence probability for congenital malformations is low, but these often cannot be calculated precisely and empirical incidence data should be utilized in order to obtain reasonable estimates.

The genetic counselor should also be prepared to interpret the calculated recurrence risk and to offer reasonable choices of action for couples with a high risk of having affected offspring.

TABLE I

Probability that Consultant is a Carrier of an X-Linked Recessive Disorder if She has No Affected Children, m Normal Sons, and is n Generations Removed from the Last Known Carrier.*

Generations Since Last Certain Carrier (n)	Number of Normal Sons (m)						
	0	1	2	3	4	5	6
1	0.500	0.333	0.200	0.111	0.059	0.030	0.015
2	0.250	0.143	0.077	0.040	0.020	0.010	0.005
3	0.125	0.067	0.034	0.017	0.009	0.004	0.002
4	0.062	0.032	0.016	0.008	0.004	0.002	0.001

*Modified from Murphy (8).

TABLE II

Recurrence Risks for Translocation Mongolism.

Karyotype of Mongol Child	Parental Karyotype		Risk of Mongolism in Each Pregnancy (%)
	Father	Mother	
21/21 Translocation	Carrier	Normal	100
	Normal	Carrier	100
D/G Translocation	Carrier	Normal	2
	Normal	Carrier	20
21/21 Translocation	Carrier	Normal	Low
	Normal	Carrier	Low

TABLE III

Risk of 22 Trisomy Mongolism According to Maternal Age.*

Age of Mother (years)	Risk to Offspring	
	At Any Pregnancy	After Birth of an Affected Child
All Mothers	1 in 665	1 in 200
20-29	1 in 3000	1 in 1000
30-34	1 in 600	1 in 200
35-39	1 in 280	1 in 100
40-44	1 in 70	1 in 25
45-49	1 in 40	1 in 15

*Based on data of Carter and MacCarthy (5).

TABLE IV

Range of Recurrence Risks in Medical Genetics.

Relative Magnitude	Percent Risk	Examples
High	100	Both parents homozygous for same recessive disease
		Carrier parent with 21/21 translocation
	50	Autosomal dominant disease with full penetrance
Intermediate	25	Autosomal recessive disease
	20	Maternal carrier of D/G translocation
		Autosomal dominant disease with less than 100 percent penetrance
Low	0-10	Congenital malformations of other than single gene etiology
		Sporadic chromosomal aberrations

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DEVELOPING SERVICES FOR DEAF-BLIND YOUTHS AND ADULTS*

By

Peter J. Salmon and Harry J. Spar

This fall, we expect to move the programs of the National Center for Deaf-Blind Youths and Adults, which are presently housed in temporary quarters in a converted section of a warehouse, into specially designed facilities that are approaching completion on a choice 25 acre property in Sands Point, Long Island, New York. The move will have to be made gradually. The rehabilitation, research, community education, and administration activities, now being carried on in the temporary facilities, will move first--probably, in October or early November. After that move, we will need to recruit and prepare a staff to operate the new residence on the campus of the National Center before the trainees can be moved from their present temporary accommodations in two of the facilities of The Industrial Home for the Blind, the National Center's parent agency. This will probably require some months. Upon the completion of that move, we will be ready to expand our headquarters' staff by adding medical, dental, optometric, recreational, and other specialized personnel as well as increasing our present professional and paraprofessional staff. While this is in process, we will be gradually increasing the trainee case load at our new headquarters. We will need to be careful not to increase the number of trainees more rapidly than the increase in the readiness of the staff to serve them well. By staff, as the term is used here, we mean everyone from administrators and porters, who offers indirect and supportive services, to professionals and paraprofessionals, who serve trainees and other clients directly. We estimate that a year and a half to two years will be required to bring the use of the permanent facilities of the National Center to full capacity.

Unfortunately, the development of sound programs and competent staff to serve deaf-blind people requires the investment of time, thought, and energy as well as the investment of money. Contrary to what some people seem to believe, the problems of the deaf-blind cannot be solved by smothering them with money or by merely adding many titles to the payroll. A consultant, for example, is not created by payroll designation, and even a well trained and experienced counselor, instructor, social worker, or any other professional cannot use his special knowledge and skill effectively in serving deaf-blind people until he has had an opportunity to learn to appreciate the communication problems, the feelings of insecurity, the barriers to effective interpersonal relationships, etc. as well as the considerable residual potentialities that can accompany severe deficits in the two major senses.

The National Center has not and will not spend money for the sake of exhausting its budget to establish its need for funds in the future. This attitude has sometimes made it difficult to obtain adequate funds on a timely basis; but we have demonstrated that we will not deliberately over budget and we believe that we now enjoy the confidence of the Rehabilitation Services Administration and that we can now look forward to very good coordination in the provision of funds and our ability to use them effectively.

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*This paper was presented at the Forty-Sixth Convention of the American Association of Workers for the Blind in July of 1973.

In a field of work as new as that of serving deaf-blind youths and adults, where virtually no experienced personnel are available for employment and little or no precedent exists to fall back upon in selecting specialized services and equipment for purchase, positions can seldom be filled as soon as funds are available for them and appropriate outside services and specialized equipment can seldom be found as soon as they are needed. Thus, the lag between the wish and the wish fulfillment in developing the program of the National Center is likely to be somewhat unpredictable.

Before discussing our plans for the immediate future, let us comment briefly on the scope and the results of the rehabilitation services offered under the program of the National Center to date. Some of our work in research, in community education, in the development of the special design features of the permanent facilities of the National Center, and in the development of service resources in the field may be brought out by your questions later or may be seen in our exhibit at this convention. We shall limit our comments here to direct services.

Currently, in the course of a year, we serve about 500 deaf-blind youths and adults. This service ranges from counseling, referral, follow-up, help in obtaining medical or other essential services, consulting with agencies interested in serving a particular deaf-blind individual and/or his collaterals, etc. to providing a full range of evaluation and rehabilitation training at our headquarters. As of December 31st last, 81 clients who had been enrolled in the rehabilitation program conducted at the National Center headquarters for some period during the approximately five years that it had then been in operation completed training or, for other reasons, had withdrawn from the program. Their statutes as of last December 31st were as follows:

16 were working in full competitive employment

20 were working in sheltered workshops

5 were training in other facilities

6 were homemakers

5 were working in family enterprises

1 was employed in a home industry

1 was in on-the-job training

5 were attending college

1 was attending graduate school

1 reentered the National Center for further training to prepare for employment as an instructor's aide at the Center

5 were awaiting placement
(1 of these is now employed in a sheltered workshop and 1 is in on-the-job training in a sheltered workshop)

6 were at home receiving services for local agencies in cooperation with National Center representatives
(2 of these are now in on-the-job training in sheltered workshops

and 2 others, who were ready for employment when they completed their training, are still at home at the insistence of their families)

1 was reclassified as "not deaf" and, upon the completion of his evaluation, was transferred to a rehabilitation center for the blind

1 was ill (has not yet recovered)

4 returned to custodial institutions

1 was retired

2 were deceased

In assessing the results of any rehabilitation program, it is necessary to take into account not only the number of clients served and the improvements that the service produced in the economic and social conditions of the clients but also the severity of the handicaps of the clients served. With this in mind, the following data will be seen as significant.

Of the clients served at the headquarters of the National Center through December 31, 1974, including those who were being served on that date, 47.4% had visual acuity of no more than 5/200 (including 28.9% who had no more than light perception). 69.1% were congenitally deaf and 89.7% showed speech discrimination scores, under optimal test conditions, of no more than 20%. (0-20% is the lowest category on the rating chart we use; and, actually, almost all of the 89.7% of the clients whose speech discrimination scores fell within this category had no ability at all to discriminate speech.) 31% either had had no education at all or had attended ungraded classes. Of the 18 clients enrolled in the program at the headquarters of the National Center last February (when this data was compiled), 3 came to the Center directly from state hospitals for the mentally ill, 2 came directly from state schools for the mentally handicapped, and 2 came without any identifiable language.

Service to about 50 clients at a time will represent the use of the National Center's permanent facilities to practical capacity. Aside from beds for resident employees, these facilities will accommodate 62 to 64 beds. A few of these will be reserved for resident students of universities affiliated with the National Center in graduate programs in services for the deaf-blind and 6 or 8 of them will generally be reserved for resident students in short-term training programs. Allowing a few vacant beds for emergencies and for the unavoidable slippage in the operation of any program, we will be able to accommodate about 50 clients at a time in the Center's permanent facilities. It is expected that some clients will remain in training at these facilities for two or three years or longer but that many, after a 6 or 8 week period of evaluation at the National Center and, in some cases, an additional several month period of basic rehabilitation training, will be able to complete their training at facilities operated in or close to their home communities by cooperating or affiliated agencies. Thus, it should be possible to enroll for service at the National Center about 100 clients in the course of a year.

We expect that the clients served at the National Center will, generally, be deaf-blind individuals with rehabilitation needs that will require a full staff of specialists in services for the deaf-blind and the kind of specially designed facilities that will be available only at our headquarters. In this way, the National Center will serve as a court of last resort for those deaf-blind clients who could not be served at other agencies. At the same time, it will provide an opportunity for developing and testing rehabilitation methods for serving severely handicapped deaf-blind persons which could be used to enhance the capabilities of cooperating and affiliated agencies in helping to serve the total deaf-blind population. The National Center, too, will serve as a clearinghouse for problems and achievements for all interested agencies serving deaf-blind youths and adults so that the experience of all of these agencies might be pooled with that of the National Center to provide a source of ideas and information that should be helpful in furthering both their collective and individual efforts on behalf of deaf-blind persons. The research resources of the National Center will be dedicated to meeting those needs for special skills, sensory aids, and information which emerge from the total efforts of all agencies interested in the rehabilitation of deaf-blind individuals and its research department will make maximum use of their experience and thinking.

During the last calendar year, the regional representatives of the National Center visited 276 agencies in the interest of serving or developing services for deaf-blind individuals. An increasing number of agencies cooperating with the National Center, often in the interest of providing training and employment for one or two deaf-blind persons living within their service areas, are contributing importantly to the expansion of resources throughout the country for serving deaf-blind people.

Another means of substantially expanding resources for providing programs of specialized services for deaf-blind youths and adults is seen in the affiliation with the National Center of selected rehabilitation agencies. The purpose of such an affiliation is to develop in each affiliated agency an ongoing capacity to serve a fairly small but significant number of deaf-blind people with its regular staff and the help of a specialist in services for deaf-blind youths and adults. Agencies that conduct sound rehabilitation programs that can be adapted to meet the needs of deaf-blind youths and adults and that have demonstrated an interest in serving this group of handicapped people are encouraged to apply for affiliation with the National Center.

The National Center is prepared to provide funds on a temporary basis to a limited number of affiliated agencies with which to meet the cost of the salary and related direct expenses of a specialist in services for the deaf-blind. Such funds are provided with the understanding that, if the work of the specialist in services for the deaf-blind in an affiliated agency proves successful in enabling that agency to serve deaf-blind youths and adults satisfactorily, the specialist will become a regular member of the staff of the agency with the cost of his services included in the regular budget of the agency within a period of about three years.

In general terms, the functions of the specialist in services for the deaf-blind are:

(1) To help meet the unique needs that grow out of the double handicap of deafness and blindness by instructing deaf-blind clients of his employing agency in the one-hand manual alphabet and the use of other methods and devices for communicating without sight or hearing, by counseling with these clients, etc.; (2) To instruct the staff of his employing agency in methods of communicating with deaf-blind persons and to consult with them on the special needs and the potentialities of the deaf-blind clients they serve so that the various members of the staff might apply their particular skills to the rehabilitation of their deaf-blind clients as nearly as possible on the same basis as they employ them in serving the rest of their clientele; and (3) To initiate and conduct, in cooperation with the regional representatives of the National Center, outreach services to locate deaf-blind individuals and to provide preliminary assessment of their needs and interests as a basis for referring them for evaluation and/or training to the National Center, to his employing agency, or to any other appropriate program, and for providing or obtaining for them home instruction, counseling, or any other services that might be appropriate to meet their individual needs.

During the next year, in addition to improving and expanding services at our new headquarters, we plan to concentrate on developing field services in the western part of the country. We hope to open two additional regional offices in that area and we shall give first priority during the next year to the consideration of applications for affiliation with the National Center from rehabilitation agencies in the western part of the country. With the assistance of cooperating and affiliated agencies and with the increase in our regional offices, we expect to be able to double, triple, or, possibly, quadruple our capacity to serve deaf-blind youths and adults within the next two or three years.*

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LOW VISION PAPERS[*]

By

Loyal E. Apple, Panel Chairman
Randall T. Jose, O.D., F.A.A.O.
Pat Carpenter
Clare M. Hood, R.N., M.A.
Eleanor E. Faye, M.D., F.A.C.S.
Beth Phillips
Roy J. Ward
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[*] Editorial Note: These papers were delivered at the Forty-Sixth Convention of the American Association of Workers for the Blind, 1975. Those by Apple, Jose, Carpenter, Hood, and Faye were presented at the Third General Session on Tuesday, July 22. Those by Roy J. Ward and Joseph J. Hennessy were presented in the Low Vision Interest Group on July 21 and July 22 respectively.

INTRODUCTORY REMARKS

PANEL ON "TRENDS IN THE DEVELOPMENT OF LOW VISION SERVICES"

By

Loyal E. Apple

Low Vision has been a longtime interest of mine and I notice it has been a longtime interest of AAWB. I will keep my remarks brief. They are in the form of a few questions.

First, are there enough differences between low vision and blindness for low vision to be considered a separate disability? We know that there are differences in physical attributes and we expect that there is usable vision. There are differences in adjustment and in society's attitude toward low vision persons. Aren't there some differences in the way we approach the communications problems of low vision, the mobility, the vocational outcomes and the recreational and personal aspects?

Another question is, what is the best practice in terms of demography, statistics and definition of the population? What is the best way to report the treatment or the rehabilitation services that low vision persons receive?

What is the best practice in terms of service to their families? What is the best practice in terms of follow-up?

Then, another question is, if there is a body of knowledge that is practical, then, is it teachable? Is there a kind of literature having to do with low vision? Is there a theory or philosophy? Is there a discipline or several disciplines involved in work with the subject area?

The Panel on Low Vision is a multi-disciplinary panel which will address itself to this and to the questions I raised previously.

WHAT IS LOW VISION SERVICE?

By

Randall T. Jose, O.D., F.A.A.O.

It is hard to estimate the number of partially sighted low vision patients in the United States. However, it is felt that there are at least 2.5 million patients who have a severe vision loss and are in need of very specialized vision care.[1] Drs. Ed. Mehr and Allan Freid use the following definition for partial sight:[2]

> Low Vision or partial sight may be defined as reduced central acuity or visual field loss which even with best possible correction provided by regular lenses still results in visual impairment from a performance standpoint.

Using this more functional definition of visual impairment, the low vision service will be directed towards helping those people who have a vision problem which prevents them from performing some task which they desire to do. If we design our vision care programs to meet the needs of this population, we are probably talking about a patient load of at least 5 million people.[3] With hardly 200 clinics or professionals identified as providing the services in the United States,[4] it is easy to see that we have a great challenge ahead of us to develop vision care programs for this group of people. You will notice that there are no numbers or field losses by degrees indicated in this definition of a population which needs vision care. I believe this must be the number 1 criteria in defining any low vision programs--do not limit yourself with numbers, degrees or other arbitrary perometers when discussing visual needs of people.[5]

The biggest problem in trying to define a low vision care program that will serve this population is that if we have a population of 5 million people, then we have 5 million very unique and different problems to solve. These problems are not solved by a single approach to vision care. Whatever system is used must be flexible and responsive to the individual's needs. To compound the problem, you will find that in each of the 200 or so clinics that are in the United States, the manner in which the individual's problem is handled will vary tremendously from clinic to clinic or practitioner to practitioner. What I consider to be a good comprehensive program of vision care for the partially sighted patient, may seem to be a lot of unnecessary "flag waving and razzle dazzle" to one practitioner and yet be grossly inadequate to another. So in trying to develop our concept of a model low vision service we must not only take into consideration the 5 million different people with their 5 million different needs but also the 200 or so clinicians and their biases and attitudes towards this important aspect of vision care. With that in mind we shall proceed to attempt to develop a basic concept of a comprehensive low vision service.

The low vision service is very flexible. You can find it in an agency for the blind, vocational and rehabilitation setting, hospital, medical center, (ophthalmological training program), optometry school, school for the blind or deaf blind, and in the private setting.[6,7] There are advantages and disadvantages for each of these locations and it would probably take the better part of a week to argue all the pros and cons of each of these particular facilities at the ideal setting. In addition you can have programs which go to the patient and the services provided in his or her environment as well as the typical method of care where the patient comes to the service.[8] So, rather than get involved in a long discourse about facilities, let us just state that the service should be provided in a facility which is accessible to a large majority of the population who need this particular service.

Who is the low vision expert? This is probably the toughest question to answer in our efforts to develop our concept of low vision care. Who is the individual who is supposed to have all the answers? Is it the optometrist or the ophthalmologist? Or maybe you are from the group who feel that low vision care is strictly the territory of mobility instructors. What about rehabilitation counselors and teachers, special education teachers, physical therapists and others who are providing direct services for the low vision patient? Obviously, the answer is no one person can be an expert. The low vision expert is quite simply an interaction. It's the total efforts of the optometrist, ophthalmologist, mobility instructor, vocational rehabilitation counselor and teacher, special education teacher, physical therapist, occupational therapist, recreational specialist, social worker, nurses, psychologists, and anyone else who can make a contribution to this individual's ability to function better and more comfortably in his present environment. It must always be kept in mind that the low vision service is a problem oriented service. There are relatively few patients who will come to you with one problem only. It will be a very rare occassion when the individual has problems that are solved strictly with an optical aid or strictly with mobility training or strictly with some other unique service offered by one discipline. It must be kept in mind by all professionals working in this low vision care service that this is a program of rehabilitation. However, we can break down the components of the low vision service into four major categories which will include almost all those people that are able to contribute to this patient's rehabilitation program. By using these four broad categories of service, we are leaving enough flexibility in the service program to allow for the integration of professional services in such a manner that the patient will always be kept foremost in mind. Since we cannot have well defined roles for each professional we will need people to fill the following services:

1. Evaluation of previous medical treatments and the need for future medical/surgical treatments.
2. Evaluation of optical aids/best residual vision.
3. Evaluation of the functional use of the optical aids.
4. Evaluation of the need for additional rehabilitation and social services.

The order in which the services are provided is not rigid. Typically the patient will enter the low vision service with an eye examination. It is during this examination that clinical data pertinent to this patient's vision problem will be obtained. Basically, the examination will reveal the stability of the disease process, the amount of intact retina that is left and the quality of the visual receptor cells in that intact retina. In essence we are answering the question, "what do we have to work with?" This should not be a cursory evaluation and should consist of several different investigations. A thorough and extensive case history should be taken. This case history should include all previous medical care and should attempt to discover how well this patient feels he functions as a sighted person. An attempt should be made to identify those problems which seem to bother the patient most at this time. Prior to the initiation of any rehabilitation or optical aid treatment programs, a complete health workup should be conducted. It should be determined that there are no medical or surgical procedures which may substantially improve this patient's ability or function visually. If we are assured that all medical/surgical treatment has been provided that is available, then we can proceed with the evaluation of the ocular/optical system. A thorough investigation of the peripheral and central fields is important in the low vision examination. This is the type of information which will be extremely valuable to further evaluations conducted by mobility instructors and others in trying to determine functional vision of this patient. It also provides information for the examiner as to the extent of magnification this particular retina will be able to receive. Before working with magnification a complete and thorough refraction must be performed. Over 60% of our partially sighted population are suffering unnecessary visual impairment because of poor refractions.[9] This is usually due to the hurried examinations conducted by many of our practitioners. A slow thorough, examination of the optical components of the visual system must be done on every patient. We want to be assured that the loss of acuity is due to the pathology involved and not a poor refraction. A series of visual acuity measurements both at a distance and near should be obtained on each patient. This allows us to make some judgements as to the patient's ability to function visually. It is also a clinical measurement which can be used as a starting point for other functional evaluations of visual capabilities in the non-clinical environment. The next area to work in is magnification. Now that we know both the extent of the retina left and the acuities that the patient is able to manifest at this time, we can design a magnification system that will allow the patient to perform those tasks which he has designated in the case history as important to him/her. Magnification can be provided in many forms and one should not limit himself to a box of aids in which to provide this important aspect of care. We can obtain magnification in spectacle form, as a hand-held magnifying device, as a hand-held or spectacle television. Once the most appropriate type of aid is determined to provide the needed amount of magnification, a training period is initiated for the patient. A loaner device may be given to the patient and a period of instruction given on the use of this loaner aid prior to the patient leaving the clinic. The patient is released from this first examination period with the loaner aid and very concise and clear instructions as to the use of that aid. Formal training programs may occur before a second clinical evaluation is made.[10] At a second visit the patient is questioned as to his success with the aid and based on the information received, a final Rx is provided. Further training is given with this final correction and the patient is questioned as to other needs that may have arisen during this period. Because of the limitations of optical aids, it is quite common for patients to need 3 or even 4 different types of aids to solve a small number of their day to day problems. This is just the clinical aspect of the vision service. While this service is being provided to the patient or shortly after its completion, functional evaluations of the patient's ability to use his eyes in his non-clinic environment should be conducted. This information can also lead to modifications of the present optical aid or the development of new optical aids to assist in his travel, educational needs or vocational needs. All during the course of the low vision examination, input should be coming from the others involved with the patient. Likewise, that information being collected by the clinician should be distributed to those other members of the rehabilitation team. There should be a constant exchange of information about this patient in an effort to obtain the best optical aids or low vision services for the needs for this individual. Most importantly, it must not be forgotten to ask the patient what he or she feels the most important and significant needs are!

It is easy to see that everyone must contribute to the entire procedure. For some patients the eye examination will be the most important aspect of their program. For others, the mobility they receive as a part of this low vision service will be the most important aspect of care they receive. Still others, will benefit most from those services provided by the social workers involved in the low vision program. The emphasis of the low vision service will change with every patient. If it doesn't, then it is not meeting the needs of the patient which we indicated was our number one criteria for the low vision service. The definition we can use for a low vision service is "an environment in which a group of rehabilitation professionals are interacting in an effort to give an individual the opportunity to function at his or her highest level of visual performance, irrespective of the extent of the loss of visual function."

Try not to get too hung up in administrative systems. As Mr. Olshansky states:

> Every system has inescapable limitations. The challenge is not to develop a perfect system, but to develop one that combines the possible, desirable and practical and that permits both staff and clients opportunities for growth.[12]

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LOW VISION AIDS: THE IMPLICATIONS OF EDUCATION

By

Pat Carpenter

It is really very simple, and can be told in a few words. The successful prescription of a low vision optical aid can mean a change of self image from blind to sighted; of reading medium from braille to print; from listener to reader; from dependence to independence.

What is involved in that simplistic statement? First the understanding that it is simplistic, that we need to add "under certain conditions" to each clause, and that a great deal of evaluation, training, and motivation must precede and follow prescription of a low vision optical aid to insure its success.

The development of the visual sense is perhaps the first thing to consider in the education of the visually impaired child. Since vision is learned behavior, development of vision must be sequential and follow the same order in a low vision child as it does in the child with normal sight. Gesell said that "The seeing eye is part and parcel of an indivisible integrated growing action system."[1] When vision develops normally, the child responds to what he sees, the hand follows the eye, and the whole motoric system is set into motion as development proceeds in an orderly series of steps. "Since vision is a complex sensory motor response to a light stimulus mediated by the eyes, but involving the entire action system--every system of the human organism is involved."[2]

Fixation is the primary visual function. The visual system seeks and holds an image. A form is perceived. The next step is visual pursuit of a form or object. The more a child looks, the more that he sees, and the more information is stored in his brain, if all systems are functioning properly. Barraga has pointed out that "the primary problem of the low vision child is that there is very little he can 'pick up' just incidentally through his visual sense. He needs to be taught the process of discrimination between the forms, outlines, pictures, and symbols which may never have been brought to his attention. This process doesn't 'just happen' when he looks; it is a complex pattern of learning, beginning with the very simplest types of visual forms and progressing gradually to more detailed patterns of visual representations."[3]

Visual stimulation and the best use of residual vision must be taught before the introduction of optical aids for improving or correcting low vision. The task of seeing can be analyzed to a series of steps:

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[1] Geselle, Arnold; Ilg, Frances; and Bullis, Glenna, Vision: Its Development in Infant and Child, Paul B. Holber, Inc., Harper and Bros., 1949.

[2] Ibid.

[3] Barraga, Natalie, Editor, Teacher's Guide for Development of Visual Learning Abilities, APH 1970.

Light perception
Form perception
Object recognition
Object pursuit
Classification of objects
Recognition of similarities
Discrimination of differences
Interpretation and cognition of symbols
Decoding of symbols--as in reading

From interpretation to decoding of symbols is a GIANT step, which some low vision children will be able to take, with the proper training. Others may not. Fundamental training in the use of residual vision is essential to good visual function and visual efficiency. Each child has a "right to use whatever vision he may have under the conditions and with the materials which ensure maximal functional vision for him."[4]

The work of Natalie Barraga and her followers has demonstrated that small amounts of residual vision can be trained for increased use. Increasing visual efficiency through developmental and sequential training is something that most teachers know how to do. It is part of most teacher-preparation programs, and it includes the Visual Efficiency Scale distributed through the American Printing house for the Blind, which provides a teacher with a profile assessing a child's ability to use his vision, and pointing out areas of weakness which need training and development. There is also a developmental sequence of activities, structured sequential lesson plans, and a teacher's guide to their use. The launching of these materials was done initially through a series of workshops and training institutes supported by the U.S. Office of Education, Bureau of Education for the Handicapped, about five years ago. Beginning teachers as well as experienced teachers were trained at the same time. This was one of the best organized national group efforts in the education of the visually handicapped, in my opinion. The same sort of national group effort needs to be launched to train teachers in the understanding and use of low vision optical aids, for reading, for work, and for mobility.

Low vision is not just an aid but a service. That has been amply pointed out to us by Dr. Jose, Dr. Faye, and Miss Hood. Dr. Jose's model of inter-disciplinary service and cooperation includes many people and many disciplines. The special education teacher is an important part of this team, working with children as well as adults. Low vision optical aids have been around a long time. Their number has increased, their range of possibility has multiplied and in general their cost has gone down. And anyone with an amateur's interest in photography realizes that the availability of complex lenses for cameras increases each month. There's a lens for every need. Some of this optical sophistication is spilling over into the field of low vision aids--with the Argus loupe available in any camera store, and at a very low price. But that's just a start--how about wide angle, zoom, telescopic and modular lenses? Possibilities are endless.

Teachers and mobility specialists of all ages are begging for increased knowledge and training in the understanding of physiological optics. They want to know how the development of visual function, and capacity to see, can be increased even further by the judicious use of optical aids. When is the best time to introduce a support system of optics? How do you stimulate and reinforce a student's motivation to use optical aids to help him see better? How do you sell what you are doing to a skeptical classroom teacher who feels very strongly that a braille student is a whole lot easier to deal with educationally than one who seems "to take forever" trying to get a picture and the words on a page into focus? And what kind of aid can help a child's mobility? My observation is that everyone is more impatient than he used to be--and that some adjustments must be made because of this fact. So the philosophy and the psychology of support to the visually impaired students needs to be sold to every teacher who has such a student in his class. The teacher of the visually impaired is the best person to do this, especially if she can enlist the support of the eye specialist, and the low vision service team in what she is doing.

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[4] Bateman, Barbara,"Visually Handicapped Children," Methods in Special Education, by Haring, Norris, and Schiefelbusch, Richard, pp. 257-300.

Parents, too, need to understand what is involved in loupes and reading aids, hand and stand magnifiers, telescopic and microscopic aids, particularly the simple fact that no one aid is going to be satisfactory at all distances for all uses, and that for a child it must be fun to use an aid to see better.

We had so much fun with Joe this year. Joe had a cataract removed, so that in one eye he had more light getting in, and he could SEE better. The doctor said so. But Joe couldn't see better. He had always been a braille student, moving about gingerly, gazing but not registering visually at all. He saw nothing below his elbows. But the teacher worked with him stimulating him to look, to see what he could see. It was a long, slow process in the beginning. One day when I was in the school he just combed my entire person with his eyes, examining my fingers, my watch and rings, buttons, and pendant. He reported happily the shape and size of each one of these, then introduced me to his collection of plastic letters, and the words and sentences he was making out of them. Joe was a second grader, who had learned braille, and did his reading and writing through that medium. He had to learn what print was from the beginning. Once he began to function within a visual framework, he and his parents went to the pediatric optometrist for examination and refraction. When this was done, and the optometrist was secure in his findings, he met with the parents, the principal, classroom teacher, resource teacher of the visually impaired, and with me. We each had a copy of his detailed examination report, and he went over it with us step by step, so that we all understood what he had found and what he proposed for each one of us to do to help Joe become a seeing child, a print reader, who might even be able to join the reading group with sighted children. Before our meeting was over, we all understood what he was talking about, and what contribution each of us would make to Joe's seeing program. It has been a great adventure all year, to follow Joe, his teacher, his family, and see the progress that is being made. The story is far from being over. Joe works more at present in print than he does in braille, but he is keeping up his braille skills. He is still discovering the world around him visually, with the aid that has been strategically placed on his glasses. We take our children and their parents on camping weekends twice a year, and last spring we all had a day's entertainment just watching Joe and his sister and his parents see the nature trail, the tree bark, wildflowers, leaves, pine cones, and underbrush. The point I would like to make though is that having an eye specialist who worked with and listened to the teacher, parents, principal and consultant was invaluable to Joe's success in using his optical aid. We are just beginning to go into the area of Joe's changing needs in mobility, which are quite different.

Anita is another one. Anita is a seventh grader who plays in the band. She started her visual adventure, using music. You know how hard it is to find brailled music to match the edition, publisher, and key that is being used by the band in a public school program. So Anita's teacher started transcribing the music with felt tip pen, using a large staff and large notes, because Anita could see it. Motivation is the key here, because Anita really wanted to play in the band. The music worked beautifully, and when Anita went to the ophthalmologist, her mother asked for a better refraction, and a stronger prescription, to help her to read more printed material. He supported her referral to the Atlanta Area Services for the Blind to their Low Vision Clinic when Dr. Randy

Jose and Dr. Robert Crouse were working together there. Anita is a youngster who enjoys life, and seems to take on new challenges easily. She is what I would like to call "bi-medial"--she reads print when she can see print and braille when she needs braille. So far this is no particular frustration for her. The optical aids she uses in conjunction with her specs have made her print work possible.

All of the teachers are pleased and excited about the possibilities that have opened up. Most of them received their training five, six, ten years ago. They are really begging for additional information and understanding of low vision aids and what they can do. They need workshops with "hands-on" experience in low vision aids clinics observing refractive examinations, visual and motor training, understanding of the effects of illumination, the range and variety of low vision optical aids and how they can be used in reading, and mobility training. There are so many low vision non-optical aids. How can they be supplemented with optical aids, closed circuit TV systems? Two or three sessions in a university classroom will not provide the experience needed. I would like to see a series of interdisciplinary workshops run by teacher preparation programs, schools of medicine and optometry, with close attention and support from specialists in motivational psychology. These should be available during summer session with tuition grants available. There are 114 Low Vision Services listed in the 1973-75 directory published by NSPB. Educators need to work with these agencies, to stimulate the cooperative effort needed to provide teachers with the knowledge they need, and eye specialists with the understanding of visually impaired children they need, to make comprehensive low vision services a reality.

A teacher can tell you how a child looks, and how he sees when reading, walking, picking up something, looking at the blackboard, carrying his lunch tray in the cafeteria. The eye specialist and the low vision aids service can provide the extra factors to improve these visual experiences.

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TRAINING OF THE LOW VISION ASSISTANT IN A COMPREHENSIVE LOW VISION SERVICE

By

Clare M. Hood

The purpose of this discussion is to define the role and function of the Low Vision Assistant, and to suggest a training program.

The current programs are the Optometric Technician Program at the School of Optometry in Birmingham, Alabama, and a proposed program at Western Michigan for mobility instructors. These programs represent training for new manpower.

We are suggesting another type of training program for people already in low vision or who want to go into low vision and who come with many educational backgrounds such as: nurses, orientation and mobility instructors, teachers, rehabilitation instructors, orthoptists. These people can use their current skills and complement them with additional training in the application of low vision principles.

Before attempting to outline a training program, the work of a low vision assistant at the New York Lighthouse Low Vision Service will be described.

We decided to have an assistant because it is impractical for the doctor to do the entire examination and training for three reasons:

1. The cost factor.
2. The number of patients that must be seen to keep up with the caseload.
3. The patient demands for time to practice under supervision. Our experience and statistics show that the patients relate better to the assistant during a training procedure.

The examination is divided into three phases:

Phase I--the doctor's exam

Phase II--the training period

Phase III--the follow-up

Admission Policy

All patients accepted for service must be under the care of an ophthalmologist and should have been seen within the year. A medical eye report must precede the appointment.

There is no other pre-screening. We have found pre-screening to be unnecessary, time consuming for the patient and staff, and a duplication of effort.

Phase I of our examination is done by the staff ophthalmologist or optometrist who:

confirms the diagnosis

correlates the vision with the potential visual function

interprets the visual field and the influence of the pathology

prescribes the aid

This takes approximately a half-hour to 40 minutes.

Phase II is the training of the patient, in the use of the prescribed aid by the Low Vision Assistant.

This occurs immediately after the doctor's examination as part of the first visit. It is the assistant's role to make sure the patient knows how to use the aid correctly and helps the patient begin to see how aids both optical and non-optical help him.

As you can see, the assistant's work is a combination of support, training and interpretation.

Support

The patient needs encouragement and a chance to expand on his needs during the time he is in training.

Training

The patient has to be trained to use his residual vision in a new way. He must be shown the mechanics of the use of the aid; how to hold reading material, to manipulate the magnifier or spectacles to adjust the lighting, to position the work. This is what is called visual training.

Interpretation

The assistant can help to interpret and reinforce to the family and patient what the doctor has told them.

Thus, the low vision assistant has a job which combines many facets; let us see what the assistant must be trained to do?

1st--To take the doctor's recommendations of aids and present these aids to the patient.

2nd--To instruct the patient in the proper use of the aids and to give the patient a loaner lens if it seems necessary.

3rd--To report to the doctor any difficulty the patient might have with the aid. Then the doctor and assistant discuss another approach based on the assistant's observation. This is very important because the skilled assistant can often pick up reactions and information that the patient may not have revealed to the doctor. The assistant then re-evaluates the new suggestions with the patient.

4th--One of the most important functions of the assistant is to connect the patient with the other services available in a multidisciplinary approach; that is to call in the rehabilitation staff, the mobility instructor, and the Social Worker when a problem persists which is beyond the limits of training of the low vision staff. . . .

and

5th--The assistant can also be responsible for appointment schedules, maintenance of supplies, and loaner lenses, reports, statistics and instruction of clinic clerks and volunteers.

Training Visits

The number of training visits may vary from 1 to 4 or more. We have found that in most instances the patient accepts his prescription after 1 to 3 training visits which are spaced exactly two weeks apart. The patient sees the same staff member at each visit to minimize errors in judgement and to avoid a break in communication. The doctor, patient and assistant confirms the final Rx.

Phase III is the follow-up.

The follow-up is defined at The N.Y. Lighthouse Low Vision Services as a means of checking to be sure the lens is correctly prescribed, fitted and used, and in general, being sure all is well.

The follow-up is done soon after the patient gets his prescription--this visit no longer involves training.

Follow-up can be done in the office or by the rehabilitation staff on the job or in the rehabilitation training situation.

There has been some discussion about doing the follow-up in the home. Follow-up home visits have been traditional. If there is easy access to the clinic, home visits are expensive, wasteful of staff time and not necessary.

If the assistant is well trained, the status of the aid can be determined at the original clinic. In situations where great distances have to be traveled, it might be feasible to have the assistant go to a regional center to do the training and follow-up.

The Revisit

Lighthouse Low Vision Service does not use the term follow-up to mean revisit. We use the term revisit to mean the patient comes in for his periodic checkup. A revisit appointment is scheduled depending upon the individual case. A person with a stable eye condition may be seen once every other year, a person with a progressive condition will be seen more often, perhaps in 6 months, at the doctor's discretion. The difference between follow-up and revisit is, that at the revisit the entire examination sequence is repeated. The Low Vision assistant is not called in at the revisit unless there is a new prescription and additional training is needed.

From this outline, we see that the low vision assistant must have a training curriculum covering the following areas:

1. History taking relating to low vision.
2. The characteristics of eye pathology.
3. Simple optics related to the plus and minus lenses. Galilean telescope, focal distance of lens, and the principles of magnification, and electronic devices.

4. Types of aids, optical, non-optical and electronic.
5. Understanding the sequence of a low vision exam.
6. Integrating patient response--patient needs, and characteristics in training. . . .

and

7. Principles of referral.

The N.Y. Lighthouse Low Vision Service is developing a curriculum for the low vision assistant who has a basic interest and who has background in education, rehabilitation or nursing. The curriculum will be a series of lectures which will cover:

I. The Clinical Definition of Low Vision
II. The Pathology as Related to Low Vision
III. The Visual Acuity as it Relates to the Examination and to Functioning
IV. Medical Relationship and Management of the Low Vision Patient
V. The Optics of Magnification
VI. The Low Vision Prescription
    a. The magnifier--hand and stand
    b. The spectacles
    c. The telescope--hand held and mounted
VII. The Non-optical Aids, Definition Of
VIII. The Supportive and Training Techniques
    a. reinforcement
    b. success and failure
IX. The Role of the Social Worker, Rehabilitation Counselor, the Rehabilitation Teacher, the Psychologist, the Mobility Person, the Classroom Teacher.
X. Office Management
    a. the appointment
    b. the record and reports (utilization of service)
    c. the statistical analysis
    d. the audit--services and fees, state and federal requirements.
XI. The Equipment

TRENDS IN THE DEVELOPMENT OF LOW VISION SERVICE IMPLICATIONS FOR REHABILITATION

By

Eleanor E. Faye, M.D., F.A.C.S.

A Functional Classification of Eye Disease for Low Vision.*

In setting up a classification of eye disease that is useful in the rehabilitation of the low vision patient, the following premise is made: that three types of information are needed for a functional classification of eye conditions:

1. Diagnosis (predictable information)
2. Visual acuity (variable information)
3. Visual field (predictable, and variable information)

1. Diagnosis

The type of eye disease suggests that there is a considerable amount of available, predictable information about the underlying cause of the disease, the medical condition of the patient and the relation of the eye disease to other medical conditions; for example, eye hemorrhages and diabetes, optic nerve atrophy and neurological diseases. The low vision worker may gain greater insight by using a method of processing medical information that includes medical and surgical treatment, diagnostic procedures and prognosis.

Systems Review

(a) Medical treatment: is systemic treatment being given (for example, antibiotics or cortisone for uveitis, insulin for diabetes, diamox for glaucoma, medication for hypertension, circulatory or cardiac conditions, medication for seizure disorders.

Is local treatment being given (for example, pilocarpine, epinephrin bitartrate, phospholine iodide, carbachol for glaucoma; cortisone or antibiotic drops for inflammations or infections).

(b) Surgical treatment: does the diagnosis involve a potential corneal graft or implant, lens extraction or implant, vitrectomy or vitreous replacement, retinal reattachment techniques, neurosurgery. Has surgery been done?

(c) Diagnostic: does the condition require electroretinography, electroencephalography, ultrasound, evoked occipital response. Is information available on field tests, static and functional visual acuity for distance and near, reading acuity. (Although the location of the field defect may be anticipated by the diagnosis, visual acuity levels may not be predicted.)

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*This paper has been adapted for publication from a talk delivered on July 23, 1975 at the AAWB biannual convention in Atlanta, Ga. An amplified version of this material will be published by Little, Brown & Co. "A Manual of Low Vision," 1976.

(d) Prognosis: is the disease stable or progressive. Is it adventitious or congenital (hereditary).

2. Visual Acuity

Visual acuity is a measurement that is a variable for all types of eye disease. No eye condition has a characteristic visual acuity.

Visual acuity is used to predict the strength of optical aid prescription, and to indicate the degree of detail discrimination available for travel vision.

Optical aids can be classified according to reading acuity measurements.

3. Visual Field

Eye diseases have characteristic patterns of field loss although the degree of loss is variable.

A map of the visual field indicates the location of the damage in the visual system, and how much of the total field is defective. Many diseases have no field loss, others have central field loss, and still others have peripheral field loss ranging from small sectors to almost total loss.

Visual field is the most important single factor affecting functional vision. The field information may suggest a potential limitation for the type of optical aid prescribed for response to an optical aid, or may warn of possible difficulty with travel vision.

Considering the importance of the visual field in a determination of a patient's capacity to function, it is practical for rehabilitation purposes to classify eye diseases according to the pattern of field loss. There are three patterns.

I. No loss of visual field
II. Central or macular field loss
III. Peripheral field loss

I. No Loss of Visual Field

There are two groups in this first category; patients who have blurred vision over the entire field, and those who have a poorly defined image centrally (without a field defect).

Diffuse Blurring

In the first subgroup vision may be blurred over the entire field with varying patterns and degrees of density. The most common causes of diffuse blurring are diseases affecting the CORNEA, LENS, VITREOUS.

Typical Conditions

Scarring of the cornea from accidents

Edema of the cornea, often the result of surgery or infection

Scarring of the cornea from ulcers or infection

Keratoconus, or conical cornea

Cataracts, especially immature ones

Vitreus hemorrhages which come from many causes.

The most common is diabetes, hypertension, leukemia, sickle cell.

Visual Characteristics of Diffuse Blurring

Primarily blurring and haze. There may be a great difference between distance and near vision . . . often near vision is quite good and distance poor. Therefore, visual acuity must always be tested not just for distance but also for near--within the reading range. Color vision is normal although somewhat dulled. Yellow has the best visibility.

These patients are greatly affected by lighting conditions and especially glare out of doors which may reduce visual acuity to bare recognition of landmarks.

All of the diseases affecting the cornea, lens and vitreous can cause varying degrees of blurring, and the vision may fluctuate which means that the patient is constantly in a state of anxiety about his performance.

In the second subgroup, vision is not blurred over the entire field. Peripheral vision is clear, but the area within the macula capable of sharpest resolution (the fovea) is not developed. The causes of this type of defective vision are usually congenital diseases affecting the macula.

Tyipcal Conditions

Albinism--complete, incomplete or ocular

Amblyopia

Congenital cone dysfunction known as achromatopsia or total color blindness

Congenital nystagmus

Visual Characteristics

Primarily lack of clear definition of details, similar to the vision of a normal eye when a distant object is too far away to see clearly, yet the vision is not blurred, just poorly resolved. The peripheral vision is not affected in ideal lighting conditions. By moving closer to objects, or holding print close to the eyes, a person with this type of visual acuity sees normally.

Lighting and glare may reduce visual acuity in this group, but basically vision is stable and the prognosis is good. No field defect can be demonstrated with gross tests.

With cone dysfunction (achromatopsia), color vision is absent, the person sees normally in the dark when the rods of the retina see best, and conversely, sees poorly in daylight unless very dark absorptive lenses are used.

Case Management--No Field Loss

Optical aids of all types would be tried and prescribed depending on the level of the visual acuity and the needs of the patient. There are no typical aids for patients with blurred vision, so that they might see spectacles for reading, hand magnifiers, stand magnifiers, bifocals or telescopes. In cases of very poor visual acuity, closed circuit television should be tried.

It is important for any of these patients to have an accurate refraction for glasses. They may also be given telescopes for distance vision, either hand held or worn in a frame. Telescopes worn high in a frame do not interfere with mobility . . . but any telescope takes special training for its use. Patients may use them for spotting landmarks or signs, but must have the correct telescope prescribed according to the visual acuity and type of vision loss.

No matter what the level of the acuity is, people with blurred vision and no visual field loss tend to travel without aids under conditions of ideal illumination. Even a person with 2/200 can be trained to recognize visual cues if the light is good, and the environment is familiar. The decision for O & M rests as always on the needs of the patient, and the visual acuity, the visual function and the degree of visual recognition of landmarks.

Nonoptical aids, large print of all kinds, playing cards, marking pens, visors, special paper can be prescribed in conjunction with optical aids.

II. Central or Macular Field Loss

Macular disease is the most common cause of visual impairment seen in general ophthalmological practice. At the Lighthouse Low Vision Service over 75% of the patients have diseases involving the macular area.

Typical Conditions

Senile Macular Degeneration
Hemorrhagic Macular disease
Macular dysts and holes
Macular degeneration, juvenile forms
Diabetic macular disease, macular edema
Some optic nerve disease
Myopia, degenerative

Visual Characteristics--Diseases of the Macula

Primarily, lack of clear central vision. Many patients can describe their scotoma or field defect. Peripheral, or travel vision remains normal as a rule.

In macular disease visible macular pathology is seen with an ophthalmoscope. On field tests, a field defect can be demonstrated in the center of vision and there is a relatively normal peripheral field.

The average person with senile macular disease has a stable visual acuity in the range of 20/60 to 20/400, which is useful vision. He usually travels well although he may need help in adapting his vision for daily living skills. The prognosis for accepting optical aids is good.

Management of patients with macular disease.

Pessimism

Many older people fear eventual blindness and are afraid to use their vision. This fear is not always expressed, especially if the patient has had many consultations and received many negative reports such as "no treatment is possible" and "there is nothing that can be done for you."

After a discussion of the diagnosis and prognosis, the doctor and rehabilitation worker should work together with the patient on a positive approach. The positive features for the patient are:

1. Generally good prognosis
2. Central field loss is only a fraction of their total field
3. Vision usually improved with correct illumination
4. Able to travel unaided
5. Potentially good response to low vision aids for reading

An important area of management in macular disease is optical aids. Most of the people with macular degeneration request reading when they come in for aids and most optical aids are for reading. Aids usually consist of some form of plus lens, or perhaps a reading telescope or an electronic device. Nonoptical aids are also prescribed. Whether a spectacle or telescope, hand or stand magnifier or a combination of these, depends on the patient's preference and requirements as well as visual acuity. Any aid, including closed circuit television, may be appropriate to prescribe for a case of macular degeneration but patients evaluated for CCTV should always be evaluated for optical aids as well. The aids most frequently prescribed at the Lighthouse Low Vision Service are first, spectacles; second, hand magnifiers; third, stand magnifiers; fourth; telescopic loupes; and fifth, closed circuit television. The correct aid cannot always be determined at the first visit. The patient often has to learn about the whole range of aids including nonoptical aids before the correct combination can be prescribed.

Multiple aid prescription is the rule for the macular degeneration patient. An active person may learn to use spectacles, hand magnifiers, telescopes and stand magnifiers.

In cases where active disease is being followed or treated, especially diabetes, the patient should not be given an expensive or complicated prescription. A simple hand magnifier may suffice during the treatment and convalescent phase of the disease.

III. Peripheral Field Loss

There are two groups in this third category; patients who have large areas of peripheral field loss involving almost the entire periphery, and those who have only a sector or a segment loss.

The visual acuity measurement doesn't mean as much as the amount or location of field loss. Field defects present by far the most serious problems for the patient whether it is in reading or mobility.

Advanced Loss of Peripheral Field

Field may be lost from a great variety of causes, some localized in the retina, others neurological.

Typical Conditions

The classic disease is retinitis pigmentosa

Advanced chronic simple glaucoma

Neurological diseases (multiple sclerosis, brain tumors, organic brain injury, stroke, trauma)

Detached retina from a variety of causes

Diabetic retinopathy in the hemorrhagic or proliferative phase

Retrolental fibroplasia, advanced retinal damage

Visual Characteristics

Primarily, great difficulty getting around because of either complete or partial loss of peripheral vision. We don't usually think how important side vision is to us . . . it is more important than central vision in the long run.

The peripheral retina is responsible for the recognition of gross objects and movement, registering potential hazards and obstacles. Even if the residual central vision is normal it is of no help when it gets no message from the surrounding retina. For ease of mobility in traveling and for orientation, central vision by itself does not provide enough information.

Another visual problem with peripheral field loss is difficulty reading with strong magnifying aids close to the eye. Because the remaining central field becomes smaller as the object approaches the eye, less and less of the printed page can be seen close to the eye. The implications of this law of optics is that, for the low vision patient who has lost peripheral field, high add spectacles cannot often be used. Unless the patient can use a weak reading add, or hand held magnifier, we must turn to another form of magnification, electronic, or closed circuit television.

For any patient who can no longer read, or read efficiently with conventional optical aids, a trial of CCTV is mandatory. It is an expensive aid, but prescribed wisely it is the only possible aid for many people with massive peripheral field loss who need high magnification.

Sector Loss

Peripheral vision may also be lost in segments so that only a portion of the peripheral field is defective. Some of these patterns of loss are predictable and regular, as in certain neurological conditions, but they can also be irregular, random and unpredictable.

Typical Conditions

Early retinitis pigmentosa

Early glaucoma

Neurological disease affecting the optic chiasm

Homonymous hemianopias from stroke (quadrant loss)

Vascular diseases of the retina (occlusion of artery or vein branch)

Early diabetes

Segmental detachments of the retina

Retrolental fibroplasia, mild or moderate forms

Visual Characteristics

Unpredictable. Patients often seem to be functioning well in some situations and poorly in others. A person who has lost lower field may travel poorly, yet read well. A person who has lost the right half of his field reads poorly, yet may travel well enough to avoid criticism. The type and location of the field loss determines the functional level. The task has to be analyzed in relation to the field loss in each individual case.

Management of Peripheral Field Loss

Any field loss is potentially more disabling for a patient than reduced visual acuity. Restoration of normal function is often not possible, even with aids and field expanding devices such as reverse telescopes, prisms or the Nightscope.

More patients with peripheral field loss will require orientation and mobility than any other group. One cannot generalize however, and each patient will have to be judged on his own merits.

Patients with segmental field losses may respond well to optical aids, especially if they have an intact paramacular area.

Mechanical Factors

In addition to the eye diseases there are a few mechanical factors affecting visual acuity not always related to a specific diagnosis, they may cause even greater reduction of vision in the presence of other pathology.

Glare

Lighting

Pupillary Size

Glare.--Glare affects patients severely, often causing poor visual acuity in bright light. Many patients benefit from dark glasses, hats with brims or visors but some patients need orientation and mobility when they are out of doors, even in cases where there is no field loss.

Lighting.--Reading requires a certain positioning of light which must be carefully worked out with the patient. Patients often complain of reflection from the page of a book or magazine, and may benefit from a tinted reading lens, or a black cardboard typoscope over the page. Insufficient lighting may reduce vision drastically, yet too intense lighting may also reduce visual acuity and cause fading of vision.

Pupil Size.--Patients on glaucoma medication may have very small pupils which cannot dilate to let in more light. These patients complain of their poor night vision, and they cannot see well in areas which are dimly lighted. They may need special training for traveling. The ophthalmologist may have to modify the type of medication to dilating drops, or perhaps surgery, or diuretics if visual function continues to be a problem.

Conclusion

Low vision means working with people who still have sight. Partial sight cannot be related to or treated as blindness because a visually oriented person constantly uses visual clues and visual memory. He has potential for independence if he gets optical or other aids, and learns to adjust to the way his vision has changed. The low vision patient may need skilled help in many aspects of rehabilitation.

In projecting service needs for the future, statistics show that people with vision far outnumber those who have no useable vision. (1) Because of this trend, the need for adequate service based on sight rather than lack of sight has forced a modification of programs, current methods and services. We can create new clinics to fill the current gap in service; but we must also train personnel to understand partial sight or the clinics will fail as they have in the past without well-trained people who understand low vision.

This means that ophthalmologists, optometrists, social workers, mobility instructors, rehabilitation counselors, teachers, nurses, technicians, each with a special skill to begin with, must gain an additional understanding of low vision by experience and instruction.

The trend for low vision in the field of rehabilitation is:

to use residual vision

to train rehabilitation personnel in basic low vision

to refer for consultations within all rehab areas

to look at the disease, the person and the training process all together

to educate ophthalmologists and optometrists to be aware of the rehabilitation potential for their low vision patients.

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NATIONAL DEVELOPMENTS

By

Beth Phillips

The interest of the American Foundation for the Blind in the provision of low vision services is not new. As early as 1924, it offered "to assist any person interested in telescopic lenses to get in touch with an eye specialist" and in the late forties/early fifties, it began to stock and supply magnifiers and "far vision" devices. An Optical Aids Research Advisory Committee was appointed. Clinical evaluation of optical aids based upon data collected from seven low vision clinics, and a study of the relationship of personality characteristics on acceptance and rejection of optical aids was conducted. A statement of principles and guidelines for community planning of optical aids services was developed and distributed.

In 1958, the U.S. Office of Vocational Rehabilitation began to provide grant support for the development of optical aids clinics, and the Foundation, feeling that its function as a catalytic agent had been served, scaled down its activities in this area. In early 1960, the National Society for the Prevention of Blindness assumed responsibility for national leadership in the low vision field. AFB's advisory committee on optical aids was dissolved and the Foundation's inventory of optical aids closed out. In 1962 the NSPB published "Standards for Low Vision Aid Facilities" and in 1966 published a booklet "Recommended Aids for the Partially Sighted."

In January 1973 at a joint meeting of representatives of the National Society, National Accreditation Council, and the Foundation, agreement was reached that AFB should again concern itself with low vision and in particular with planning and promoting a nationwide delivery system.

An Ad Hoc Advisory Committee on Low Vision Services was formed and at its first meeting in March, 1974, the Committee outlined the components of a viable low vision service and estimated the population needs for service (upon the basis of Lou Goldish's figures) as about five million people with an increase per year of 10% (500,000) annually. It was estimated that about half of the total persons eligible might actually come for service i.e., 2.5 million with an annual accretion of 250,000.

The 1972-1973 survey conducted by the National Society for the Prevention of Blindness found a total of 114 low vision aid facilities. In general these were clustered in the larger cities--the largest numbers on the eastern seaboard, east north central region and the pacific coast. 54% were located in medical centers, 18% in agencies serving the blind and 11% in colleges of optometry. As in any survey, not all of the centers providing services completed the questionnaire.

Refractive services were provided in 103 of the 114 facilities reporting. Residents in opthalmology participated in the provision of services in 52, senior students in optometry in 13. Patients were examined and aids prescribed by both opthalmologists and optometrists in nine of these centers.

Staffing varied widely. In some facilities examination, prescription and instruction were provided by a single person, in others by two, three or more. Staff included social workers in 46 facilities, opticians in 44, registered nurses in 40, orthoptists in 28, reading or optical aid assistants in 19, opthalmic assistants in 11, psychological or rehabilitation counselors in 6, optometric technicians in 3, special educators in 3. Although 21 agencies for the blind reported low vision services, specialized personnel i.e., mobility, communication and rehabilitation teachers were noted as involved or available in only 5.

Approximately one-half of the facilities provided services less than one day per week. The number of patients seen varied from one per month to 45 per week. Low vision facilities in the Middle Atlantic states reported the largest number of persons receiving services and somewhat more than half as many were served in the New England and East North Central states respectively. In descending order, the number of persons receiving services in other areas was as follows: Pacific, South Atlantic, West North Central, East South Central, West South Central and Mountain states. Not all facilities reported the number of low vision patients who were seen. Low vision care that was provided by individual ophthalmologists and optometrists as part of their office practice was not included in the survey. Upon the basis of the figures available, however, it can be estimated that fewer than 10,000 persons received services in 1972-73. Whether or not Goldish's low vision population figures of 5 to 6 million people are realistic, it is obvious that the number of persons presently being served is woefully inadequate.

A second meeting of the Ad Hoc Advisory Committee was held in December, 1974. Members agreed that in order to expand and improve services, education of personnel was of highest priority. Personnel include:

Ophthalmologists and Optometrists

Opticians

Low Vision Specialists

Social Workers

Orientation and Mobility Specialists (Peripatologists) and Rehabilitation Teachers

Administrative and support staff

It was also agreed that there can be no one "ideal" clinic. Regardless of location--whether in an agency, hospital, or store front--there must be interrelationships between agency, hospital, optometry, ophthalmology. A low vision service is a rehabilitation service in which the goals are to provide maximum visual efficiency and the maintenance or development of the greatest degree of independence of which the individual is capable. Services that are required and methods of delivery of services may vary but a viable low vision service requires, in addition to interested and knowledgeable personnel, a wide base of referrals, training, loan, follow-up, and supportive services.

Over the past year, expansion of services to include a multi-disciplinary approach has taken place or is in the process of occurring in seven or more facilities and the establishment or plans for development of 13 new low vision centers have been reported.

In April of this year, on behalf of the AAWB, AFB, and the Blinded Veterans Association, the Foundation's Governmental Relations Office submitted a statement to the Subcommittee on Health, Committee on Ways and Means, U.S. House of Representatives. This statement endorsed enactment of a comprehensive national health insurance program with special provisions to include coverage for low vision services or, if a national health insurance program is not enacted, improvement of Title XVIII (Medicare) of the Social Security Act to include special services. At least one local agency for the blind is exploring with its area Blue Cross Carrier the possibility of providing coverage for low vision services.

The Visual Science Information Center, University of California, Berkeley, lists over 100 articles concerning low vision aids and training which have been published over the past five years in ophthalmological, optometric, optical and blindness journals and periodicals in this country. Three books have been published: The Low Vision Patient by Dr. Eleanor Faye (Grune & Stratton, 1970), a Guide to the Care of the Low Vision Patient edited by Dr. Julian Newman (American Optometric Association, 1974), Low Vision Care by Drs. Edwin Mehr and Allan Freid (Professional Press, 1975). At least three informational films have been produced and additional books and articles are in various stages of preparation.

A Low Vision Clinical Society has been organized in the American Academy of Ophthalmology and in addition to the Society meeting the Academy's annual meeting last year included exhibits and continuing education lectures on low vision. A Diplomate in Low Vision has been established by the American Academy of Optometry and a block of continuing education courses as well as a special interest group meeting, is included in its annual session. Low vision has been included in the program of two or more rehabilitation counselor's meetings, AEVH and area AAWB meetings and a few symposiums. Short courses and informal training are being given in some of the larger facilities.

Low Vision is currently included in course work and/or clinical experience in two or more Orientation and Mobility curricula. Low vision clinic experience is provided for students in three or more special education teacher preparation programs. New graduates of all schools of optometry and physicians completing their specialty training in 50 of the approved residency programs in ophthalmology are being acquainted through course work and/or clinical experience with what can be done to help persons make the best possible use of their residual vision. All graduates cannot be expected to be interested in providing such services themselves but if they are knowledgeable about where these services exist, they can be expected to advise and refer patients to them.

What is needed to improve and expand services?

Instructional materials and programs for training of existing and additional personnel.

Guidelines for the establishment of comprehensive services.

Evaluation of the effectiveness of services.

Compilation of information concerning initial and operational costs.

Analysis of local and regional needs, location and the types of services that are needed including sources of aids.

Involvement in local, state, area, regional and national planning for health care services.

Provision of reimbursement for aids and services.

Education of other professionals concerning the values and availability of services.

Improved community relations and referral systems.

Compilation of information about low vision, services, aids, and utilization, in a centralized library reference and loan service.

Quality control, evaluation of optics of aids, and careful evaluation of sophisticated aids that are currently available or are being developed e.g. CCTV.

Research into more effective ways of measuring, training, and utilizing usable vision.

Education of the public concerning availability of services.

One of the functions for which AFB was founded, was to serve as a centralized point for the collection and dissemination of information. We appreciate your keeping us informed of developments, changes and needs across the country, and look to you for information and assistance in expanding the low vision services delivery system.

A LOW VISION PROGRAM--A MULTI-SERVICE COMMITMENT

By

Roy J. Ward

It was with a great deal of pleasure that I received and accepted your invitation to discuss low vision programs--a service that has meant a great deal to me personally and to countless thousands of others. While reflecting on what has happened over the past thirty years to enable partially sighted persons to use their vision more effectively, I became painfully aware of the number of years which were added to my personal calendar. At the same time, I experienced a tremendous realization of what has happened since an activity which was not even a discipline thirty years ago has now become a major, meaningful and extremely important service to growing numbers of partially sighted individuals.

In this year of 1975 and, indeed, for a good many years now, it has become an accepted fact that partially sighted persons should use their residual vision and are encouraged to do so. For those who need them, there are growing numbers and types of more and more sophisticated optical aids in the forms of spectacle lenses, hand magnifiers, stand magnifiers, head-borne magnifiers and electronic devices--all to assist in more extensive reading. In addition, there is an ever increasing variety of distance aids, both hand held and in spectacle form, to improve distance vision. Sophisticated examination and service programs have been developed to maximize the prescription of the most appropriate aids and to ensure that those who receive them learn to use them as efficiently as possible.

Thirty years ago this was not the case. The prevailing opinion among many medical experts, professionals in the field and lay persons was to caution them against overuse of their residual vision. Phrases such as "sight-saving," "eye strain" and "rest your eyes" were common place terms heard almost everywhere. As a result, those partially sighted persons who used their vision extensively for reading did so usually over the objections of parents, teachers and others with whom they associated. Indeed, it was not uncommon to teach partially sighted persons with good vision to read braille or, at best, to use large print books when they were perfectly capable of reading regular print.

World War II probably began to bring about changes in this concept and advances in ophthalmological research certainly made their contribution. I have always felt that a rather significant contribution was also made by a man who is seldom, if ever, mentioned in reference to low vision aids. He is Chick Ritter, who in the late 1940's was in charge of aids and appliances for the American Foundation for the Blind. In the course of his activities, searching out aids of all types to enable blind and partially sighted persons to function more independently, Chick became intrigued with the idea of assisting partially sighted persons to read more extensively. He gathered together what few hand magnifiers he could find that appeared to be helpful and started to show them to partially sighted persons with whom we came into contact. The results were encouraging; but recognizing that his contacts were very limited, he approached representatives of the Industrial Home for the Blind in Brooklyn and the New York Lighthouse in Manhattan and encouraged them to start programs through their agencies. The idea was new and met with considerable resistance but both agencies began to utilize some hand magnifiers as part of their service programs to partially sighted persons. Out of this very inconspicuous and unprofessional beginning grew two of the major low vision programs in the United States.

What has happened since then is history which is well documented and which many of you probably have read and are as familiar with as I am. Low vision programs have come a long way since this simple beginning which usually involved an eye examination, a special low vision examination, the prescription of a reading aid or distance aid and some words of advice on how to use it.

Probably the greatest single advance which has occurred over the years is the change in status of the low vision program. Originally, it tended to be a somewhat specialized and isolated activity within either a hospital setting or an agency for the blind. In neither case was there much of an attempt to relate the low vision examination and program to other agency services which might also be helpful to the low vision patient or which, more importantly perhaps, might support and supplement the low vision program. Numerous articles in recent years have attested to the importance of making the low vision program a team effort involving many disciplines within the agency for the blind and the evidence is unquestioned that where this is done the results are worth the time, effort and money devoted to it.

The Low Vision Program of the Virginia Commission for the Visually Handicapped is illustrative of one type of low vision program which utilizes many agency resources to maximize the benefits derived by those receiving optical aids. The Commission's Low Vision Program began in 1957 with a grant of funds from the Office of Vocational Rehabilitation of the Department of Health, Education, and Welfare. The Low Vision Clinic was established in Richmond operating one evening a week at the agency headquarters. The examiner was a senior resident in ophthalmology at the Medical College of Virginia who continued as the examining ophthalmologist for several years after completing his residency. A staff member of the Commission served as a liaison person and assisted in making appointments, preparing patients for the examinations and assisting them in securing aids afterwards. This staff member had a full time assignment with the agency as a Rehabilitation Counselor and, indeed, most of the persons examined in the Clinic during the first few years were rehabilitation clients. They came from all over the state and frequently had to stay overnight because of the lengthy travel involved. When hand magnifiers were prescribed, the agency dispensed them at cost to the individual; when spectacle lenses were prescribed, they were secured through a working agreement with a local optician. There was little, if any, follow-up involved in the program.

Over the years the structure of the program remained essentially the same although a number of improvements were accomplished. The working agreement with the Medical College remained in effect and senior residents in the Department of Ophthalmology continued to be the examining ophthalmologists. An agency staff member served as the liaison person and the programs were changed from evening to daytime. Also, more intensive efforts were made to secure information on patients in advance of their examination and, where possible, the purpose for the examination was identified. This was particularly important in the case of school age children. Other improvements which were accomplished included a greater effort to provide follow-up services and the first steps toward involving other agency staff in the low vision program. The latter was accomplished in several ways. New staff members were given the opportunity to attend a low vision clinic and to observe the examinations. They also had an opportunity to meet with the low vision Coordinator to discuss the programs in greater depth. In addition, low vision examiners were given opportunities periodically to lecture at staff meetings and the low vision Coordinator met with agency staff either on a departmental basis or with several departments simultaneously. As a further step, field staff such as Education Consultants, Rehabilitation Counselors and Rehabilitation Teachers were involved in the follow-up program since they were better able to have contact with patients who were their clients and since the Coordinator had other full time responsibilities with the agency.

In the last seven or eight years much more rapid progress has been achieved. Decentralization of the program has been accomplished. The initial program in Richmond was moved from the agency to the Clinic location of the Medical College of Virginia, with the agency Coordinator continuing to work as liaison and with the agency providing clerical staff to make all appointments, keep all records and provide other clerical support. Working agreements were developed with private ophthalmologists who had formerly been residents at the Medical College and who had been trained in the program. In this way, low vision services were ultimately expanded to three more distant parts of the state making them much more readily accessible to many other individuals. A working agreement was established with the Ophthalmology Department of the University of Virginia Hospital and a low vision program was initiated at that institution. Also, a working agreement was developed with the George Washington University Hospital, Washington, D.C., which now examines some residents of the Northern Virginia area.

It was not until 1971 that the agency was successful in securing funds from the General Assembly to employ a full time low vision coordinator with full time clerical support for the program. Since that time, advances have been much more rapid. Some of the working agreements mentioned above have been consumated since the arrival of the full time coordinator and two of the private ophthalmologists who originally were examining in their own offices are now examining in clinic settings in local hospitals. Some of the other innovations and improvements which have occurred are the following: agency field service staff (Intake Workers, Education Consultants and Specialists, Rehabilitation Counselors, Rehabilitation Teachers and Social Workers) have had screening kits made available to them to be used as a rough screening device to ascertain whether clients appear to benefit from magnification and, in a very superficial way, to assess their possible interest in utilizing specialized optical aids. The results to date have been rather positive. A considerable number of clients who originally showed little interest in undergoing low vision examinations were apparently motivated to do so once they realized that they could see better with one or more of the hand magnifiers in the screening kit. At the same time, no individual who expressed interest in an examination has even been ruled out because he or she did not appear to respond based on the screening performed by the staff member. In addition to benefits to the clients, it appears that the participation in the screening program has had a desirable effect on staff members by making them more alert to the possible benefits which their partially sighted clients can derive through more effective use of their residual vision and a resultant increase in the number of referrals which they made to the low vision program.

The follow-up program has been strengthened immeasurably. The full time Coordinator is responsible for making appropriate arrangements and does as much of it personally as possible. Where personal follow-up cannot be provided, it is the Coordinator's responsibility to plan out the activity through an appropriate field staff member or volunteer and to receive report backs from the individual who actually performs the services.

Agency wide there is much greater awareness and acceptance of the fact that the successful low vision program involves all agency staff who work with an individual. The Education Consultant or Specialist relates the low vision program and the use of appropriate aids prescribed for children to the classroom, playground and extracurricular activities of each student and frequently works with parents to ensure that aids are used appropriately at home. Mobility Instructors supplement the low vision examination, particularly as it relates to the use of distance aids, since they are in a unique position to assist trainees in learning to utilize distance aids as part of their travel training. Rehabilitation Counselors have become much more aware of the expanded job opportunities available to partially sighted individuals who are enabled to read and, also, to see better at distances through the use of appropriate optical aids. Rehabilitation Teachers relate the clients' use of appropriate aids to the many specialized areas of instruction which they provide for many agency trainees.

Since the opening of the Virginia Rehabilitation Center for the Blind in 1971, a new and fertile opportunity for the team approach to low vision services has been identified. Students are at the Center on a residential basis and, therefore, can be observed much more closely in terms of their functional residual vision, their needs for aids and their use of appropriate aids once prescribed. The staff meetings at the Rehabilitation Center form an ideal setting in which to fully exploit the multi-service team approach to the low vision program. One added activity which can be incorporated at the Rehabilitation Center much more successfully than in the field is the issuing of aids to clients on a loan basis when it is not certain to what extent they will benefit from optical aids or how well motivated they are toward using them.

The low vision program currently operating in Virginia is far from an ultimate one. Those involved in agency administration, those involved in the direct service and those peripherally involved through the agency team effort all see many improvements still to be accomplished. Some of them are the employment of two field staff members who can function on a much more intensive basis in screening, in preparation of patients for examinations, in follow-up services, in public education and in closer linkage and coordination with other services delivered by the Commission and, indeed, those delivered by other community agencies which are important and beneficial to blind and severely visually impaired individuals. Another short term objective is the intensification of the low vision program at the Virginia Rehabilitation Center for the Blind. Negotiations are presently underway with an optometrist who will conduct low vision examinations at the Center after appropriate ophthalmological examinations have been secured. He will also assist staff members in a more effective follow-up program. Yet another objective is to bring the low vision service to larger numbers of older visually impaired individuals. Beginning steps to accomplish this are already underway in association with a special project currently in progress in the metropolitan Richmond area. The experience derived from this project will be applied as the opportunity presents itself on a statewide basis. Finally, expension into thus far lightly implemented services is to be explored. One such area is the use of distance magnification in spectacle lenses to enable partially sighted persons to secure drivers licenses. This activity which is already underway in many states is receiving careful study in Virginia. While it goes without saying that there are many benefits which can accrue to visually impaired individuals who are able to drive, there is still a great deal of concern on the part of many persons about the wisdom of permitting them to do so. Those concerns exist to a degree within the Commission for the Visually Handicapped but to a much larger extent are concerns of the State Division of Motor Vehicles. The Commission's low vision staff have secured a considerable amount of information on the subject and have shared it with officials of the Division of Motor Vehicles. That agency, with its Medical Advisory Council, is presently studying the matter carefully.

The low vision program in Virginia, like other such programs throughout the United States, has come a long, long way in a relatively short span of time. It is not cited as the ultimate in low vision programs but is one example of a way in which low vision services can be made available on a statewide basis to those who need them. In the speaker's opinion, while the low vision program based in an agency for the blind has many advantages, it is not the only way that such a program can be organized, administered and implemented successfully.

What seems to be of transcending importance is that any low vision program contain the following elements: (1) a thorough ophthalmological examination, (2) appropriate screening of candidates for a low vision exam and preparation of these patients for the examination, (3) a thorough and competent low vision examination which will include both reading and distance aids, (4) appropriate counseling of patients, family members, school personnel, employers and others with whom patients come in frequent contact, (5) the involvement of all appropriate special services staff of the agency for the blind and staff of other community agencies as their assistance may be appropriate to fully meet the needs of the visually impaired individual, (6) a thorough follow-up program to ensure that the person who receives a prescription or who even borrows an aid while going through the process of selecting the most appropriate prescription derives maximum benefit from the aid or aids, and (7) the assignment to the low vision program of a full time coordinator employed by an appropriate agency for the blind to ensure that a comprehensive program is made available to all patients.

If the above components are included in a low vision program, there is no reason why it cannot be successful in a variety of organizational frameworks.

A PRAGMATIC APPROACH TO THE ORIENTATION AND MOBILITY NEEDS OF A LOW VISION CLIENT

By

J. J. Hennessey

The Western Blind Rehabilitation Center admitted its first blind veteran on July 19, 1968. The majority of the veterans admitted to the Center during its early years of operation had very little, if any residual vision. In 1971 it was estimated that 30% of our admissions had some useable vision. Currently we estimate that about 70% of the individuals which enter the WBRC have functional vision. It was this drastic turn around in the nature of our population which necessitated the formulation of a functional low vision evaluation and training program in Orientation and Mobility.

By 1970 we became fully aware of our inadequacies with respect to meeting the mobility needs of our low vision students. It was this general awareness of inadequacy which prompted the staff to begin to formulate a functional low vision evaluation. Our initial efforts were directed toward establishing a procedure which would help us identify how well an individual could "see" and under which circumstances he could "see" best. We endeavored to evaluate how well the individual could see by placing him in various environments and asking him to identify or describe as many predetermined objects as he could, from a fixed position. These early evaluations helped us in that they provided the staff with a formalized procedure which assisted us in dealing with our inadequacies. Unfortunately the evaluations did not provide a great deal of insight into the individuals mobility needs.

Gradually the staff began to adopt the position that an individual's ability to identify specific objects at previously measured distances rarely correlated with his orientation and mobility capabilities. This drift in philosophy was reinforced by the realization that individuals who scored identically on the evaluations infrequently functioned at a similar level of proficiency. Naturally, we were aware of the numerous factors which contributed to these discrepancies. It was this awareness which enabled us to realize that merely identifying the individuals visual capabilities was not the solution to the problems surrounding the orientation and mobility needs of the low vision student. Thus, we set out to identify those aspects of low vision travel which we considered to be essential for safe and efficient mobility. The following material is the result of the staff's effort to identify the aspects which are most likely to create problems for the low vision traveler.

The mobility skills which we considered essential were enumerated and organized under twelve principle problem areas. The following problem areas and subheadings are not intended to be listed in order of importance.

1. LINE OF TRAVEL
    A. Regular sidewalk
    B. Rural
    C. Gait and balance

2. OBJECT ADVOIDANCE
    A. Overhead
    B. Scanning (left/right)
    C. Low
3. DROP-OFF DETECTION
    A. Curbs/stairs
    B. Irregularities of walking surfaces
4. STREET CROSSINGS
    A. Line of direction
    B. Use of traffic
5. ADAPTATION TO CHANGES IN LIGHTING
    A. Shadows/glare
    B. Indoors to outdoors and vice versa
    C. Underpasses and tunnels
6. VISUAL IDENTIFICATIONS OF LANDMARKS
    A. Gross (building/skyline)
    B. Detail (street signs, store signs, addresses, etc.)
    C. Color/contrast
7. TRAVEL IN CROWDED AREAS
    A. Indoors
    B. Business areas
8. USE OF PUBLIC TRANSPORTATION
9. ATTEMPTS TO USE INADEQUATE VISION
10. INCONSISTENCY BETWEEN VERBAL AND OBSERVABLE BEHAVIOR
11. NIGHT TRAVEL
12. ORIENTATION SKILLS

Once we had identified the factors which we considered essential, the next step was to devise a method of identifying those factors which were adversely affecting the individuals independence. We accomplished this identification by designing a series of lesson plans which place the individuals in adverse situations. These situations require them to deal with the environment in a manner which reveals their weaknesses. Our intent was to design a system where each lesson plan would provide the individual with exposure to a variety of travel situations.

It was felt that observing the individual in diverse situations would assist us in identifying his problem areas. The lessons vary in difficulty from relatively simple to very complex orientation and mobility problems. Included in each lesson plan is a list of "specific observations" which pertain to the individual situations incorporated into each particular lesson. Examples of the lesson plans and specific observations are contained in Appendix A.

Upon return to the Center, the instructor records the results of the evaluation in the individuals folder. The recording process is accomplished through the use of two forms. The first form (Appendix B) is a face sheet which summarizes the findings of the entire evaluative process. It consists of a series of horizontal columns adjacent to an outline of the major problem areas and their appropriate sub-headings. In addition to the horizontal columns there is a series of numbered vertical columns which correspond to the various lesson plans.

For example, if an individual experienced difficulty with curbs, overhead obstacles, shadows, etc. in Lesson #3, the incidents would be recorded by placing a ✓ in the square of the appropriate intersecting columns. The fact sheet displays the weakness trends which have been observed throughout the evaluative process. This form has proven to be especially helpful in providing consistancy of instruction in that it provides substitute instructors with a synopsis of the individual's problems.

The second form (Appendix C) provides the instructor with an apportunity to document the cover sheet through the use of the traditional narrative commentary. Each time the student manifests a particular problem, it is recorded under the appropriate heading. The date, lesson # and the circumstances surrounding the incident are recorded for future reference and consideration.

Upon completion of the evaluative process, the instructor conducts lessons which emphasize situations designed to resolve the individual's orientation and mobility problems. This is accomplished through the use of various distant low vision aids, scanning techniques, orientation concepts, night lessons, public transportation and cane techniques if they are indicated.

Although our evaluative process has been helpful to us, we do not view it as "the" solution to the problem of evaluating the orientation and mobility capabilities of low vision individuals. This paper has been prepared with the hope that it would lead to an exchange of ideas on a subject which requires a great deal of additional development.

APPENDIX A

MENLO PARK CIVIC CENTER ROUTE

TO BE READ TO STUDENT PRIOR TO LEAVING
(Starting Point: East entrance to city council chamber, Menlo Park Civic Center)

Take the stepping stone walk way around the council chamber building to the left. Cross the small bridge and follow the sidewalk heading west so that you walk past a building on your left and a parking lot on your right. This sidewalk will take you to Alma Street where you will turn north (right). Walk north to the first stop sign at Ravenswood and cross the street.

Turn and walk west (left), crossing the RR tracks and first street (Merrell). Turn north (right) until you come to an intersection where the street makes a jog to the right. Turn right and cross Merrell Street. Continue around the jog, keeping the parking lot and tracks on your right until you can locate a yellow wood frame building which is the Chamber of Commerce Building. Go inside and ask for a city bus schedule.

RETURN: Continue north along the RR tracks to the next street. Turn and cross the RR tracks and first street which is just beyond the RR tracks. At that point turn and walk south until you relocate your starting point.

SPECIFIC OBSERVATIONS:

1. Does he have difficulty with uneven walking surface?

2. Does he have difficulty crossing RR tracks?

3. Are street crossings safe and efficient?

4. Does he have difficulty with poles or other objects in sidewalk?

5. Does he have difficulty with changes in lighting, shadows, glare, indoor vs. outdoor?

6. Is he able to visually locate landmarks and visually relocate starting point?

7. Is he able to follow instructions, use compass directions, and remain oriented?

General Comments:

APPENDIX A

O'CONNOR-MANHATTAN BUS ROUTE

TO BE READ TO STUDENT PRIOR TO LEAVING
(Starting point: SW corner Euclid and O'Connor)

You are to take the #50 bus to the Stanford Shopping Center. To Locate the bus stop, walk south on the west side of O'Connor for one block. On this corner, you will find a dry cleaner establishment. Locate the front door which faces south on Manhattan and wait for the bus by the curb. Once aboard the bus, you may seek aid from the bus driver or fellow passengers.

Upon arrival at the shopping center as you exit the bus, you will be facing west towards the Emporium Department Store. Proceed to the front entrance, turn right and locate the corner of the building. At this corner, turn left and proceed west into the mall area. Continue west until you locate Woolworths. Go inside, find the snack bar and purchase a cup of coffee.

To return, go back to where you got off the bus. Locate the crosswalk and proceed east towards a parking lot and locate a low, brown, wooden building where you may board the #50 bus for the return trip. Take the bus back to O'Connor and Manhattan. Return by crossing Manhattan and proceed north along O'Connor until you locate the starting point.

SPECIFIC OBSERVATIONS:

1. Does student follow directions and remain oriented to compass directions?
2. Can the student read bus numbers and letters effectively?
3. Does student solicit aid from passengers or bus driver?
4. Does student exhibit safe, efficient procedures in boarding and exiting bus?
5. Does student visually identify landmarks (Emporium, Woolworths, brown bus stop building, etc.)?
6. Is student able to reverse route and relocate starting point?

General Comments:

APPENDIX B

Problem Areas	Lesson - 1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Line of Travel																	
Regular Sidewalk																	
Rural																	
Gait & Balance																	
Project Avoidance																	
Overhead																	
Scanning left/right																	
Low																	
Drop-Off Detection																	
Curbs/Stairs																	
Irregularities of walking surfaces																	
Street Crossings																	
Line of direction																	
Use of traffic																	
Adaptation to Changes in Lighting																	
Shadows/Glare																	
Indoors to Outdoors & Vice Versa																	
Underpass/Tunnel																	
Visual Identification of Landmarks																	
Gross (Bldg., Skyline)																	
Detail (St. sign, etc.)																	
Color/Contrast																	
Travel Crowded Areas																	
Indoors																	
Business Areas																	
Use of Public Transportation																	
Inconsistency between Verbal and Observer Behavior																	
Attempts to use Inadequate Vision																	
Night Travel																	
Orientation Skills																	

APPENDIX C

DOCUMENTATION OF COVER SHEET

LINE OF TRAVEL

OBJECT AVOIDANCE

DROP-OFF DETECTION

STREET CROSSINGS

ADAPTATION TO CHANGES IN LIGHTING

VISUAL IDENTIFICATION OF LANDMARKS

TRAVEL IN CROWDED AREAS

USE OF PUBLIC TRANSPORTATION

INCONSISTENCY BETWEEN OBSERVED AND VERBAL BEHAVIOR

ATTEMPTS TO USE INADEQUATE VISION

NIGHT TRAVEL

ORIENTATION SKILLS (Remember and follow instructions, use of compass directions, etc.)

THE BEST OF THE PAST
FOR THE PRESENT

NUMBER TEN OF A SERIES
OF REPRINTS*

REHABILITATION CODES

By

Maya Riviere

---

*This Series, published in BLINDNESS ANNUALS of the American Association of Workers for the Blind is an effort to preserve classic and landmark literature of blindiana.

Previous Items in the "Best of the Past" Series

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Number 2, 1966.	Letter on the Blind for the Use of Those Who See. Denis Diderot. 1749.
Number 3, 1967.	The Blind as Seen Through Blind Eyes. Maurice de la Sizeranne. 1888.
Number 4, 1967.	An Essay on the Education of the Blind. Valentin Haüy. 1786.
Number 5, 1968.	The War of the Dots. Robert Irwin. 1955.
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Number 8, 1971.	Guide for a Suitable Treatment of Blind Children from Their Earliest Youth on in the Circle of Their Families and in the Schools of Their Home Communities. Johann Wilhelm Klein. 1836.
Number 9, 1973.	One Hundredth Anniversary Papers Honoring the Anglo-American Parentage of the Royal Normal College and Academy of Music for the Blind (1872-1972). Part I--The Cradle of the Outlook's Founder. C. Warren Bledsoe. Part II--Fighting in the Dark. Dinah Mulock Craik. Part III--Reminiscences of the First Girl Student. Amelia A. Campbell. Part IV--Reminiscences of a Concert Artist Graduate. Alfred Hollins. Part V--Notes on Her Work as Superintendent of the Classes for the Blind in the Board Schools of London. Mary Caroline Greene. 1902.

REHABILITATION CODES

CLASSIFICATION OF IMPAIRMENT OF VISUAL FUNCTION

Final Report
1968

Grant No. NB 05398
National Institute of
Neurological Diseases
and Blindness

Maya Riviere, D. Phil. (Oxon.)
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New York, N.Y. 10023

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Retrospective Preface

In the age of standardization and collation we are retrospectively delighted with this publication of the Rehabilitation Codes and the Classification of Impairment of Visual Function.

The Treatment of the whole human being, his emotions, motivation and physical defects are all interrelated with his performance. In an attempt to devise a method for measuring and recording the visual factors of these parameters a working Committee of distinguished members from the ophthalmologic, optometric, social work and all the ancillary fields working with the visually impaired labored over four years to produce that section of the Rehabilitation Codes.

While studying the visual problems, the Committee bore in mind that they wanted to evaluate the total human being, all his ills and foibles. Such data had to be presented in a uniform and practical manner. The records were constructed to present the patient's status over a period of time, utilizing a uniform examining and computerized recording system. It was envisioned that such records would be utilized throughout the nation and could be retrieved for study when needed.

Standard nomenclature and procedures for measurement were particularly difficult because we wanted to make them accurate and reproducible.

This herculean task took four years to do and we believe was done quite well. The Committee knew well the pitfalls of the standard definition of blindness, the lack of research to coordinate these measurements with the patient's needs and performance. These problems were faced up to and within the Codes we have produced the most workable and to our knowledge only document in this area. Certainly some criticism could be levelled at particular points but it would in general be nitpicking. Adoption of such a code for rehabilitation would go far to making clinical records not only more understandable but useful throughout the nation.

While some small scale testing of this has been done, it only remains for large scale testing and adaptation for this system to implement its use.

Richard E. Hoover, M.D.

Roy O. Scholz, M.D.

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(1) Research Grant No. NB 05398

Short Title:

CLASSIFICATION OF IMPAIRMENT OF VISUAL FUNCTION

(2) Name of Principal Investigator: Maya Riviere, D. Phil. (Oxon.)

(3) Name of Sponsoring Organization: The Rehabilitation Codes, Inc.

(4) Period Covered by the Report: June 1, 1965 - May 31, 1968

(5) Date of Preparation of the Report: 1969

(6) Summary Statement:

This is a final report on a project to develop a descriptive classification for impairment of visual function, differentiated from defects of vision. The classification was designed to follow the pattern established for the Impairment Code of the Rehabilitation Codes longitudinal records system, which was under development from early 1957. In rehabilitation the multiprofessional staff need to base service upon the person's human problems, rather than upon a diagnosis of pathology or defect. The Impairment Code provides them with a means of interpreting the clinicians' examination reports in terms of the individual's need for and response to service throughout the rehabilitation process.

This investigation was supported by PHS grant No. 05398 from the National Institute of Neurological Diseases and Blindness for the period June 1, 1965 - May 31, 1968.

REHABILITATION CODES

DEFINITIONS

1967

The Rehabilitation Codes describe the person living in the context of his family, neighborhood, and community group.

Function refers to the use of the person's faculties as a human being, not to separate activities or performance of a limb, a sense, a bodily organ or system.

Normal refers to the statistical average or "norm," not to any unimpaired condition. Within the norm there is a range of function which is accepted as "unimpaired" function.

Impairment - is any deviation from the normal human use which a person should be able to make of his faculties.

It may be caused by one or more developmental defects, disease, or injury, or as the result of or reaction to the cultural environment where the person lives.

The eyes - which are organs of sense - perceive light and so are said to have "vision": the human use of vision i.e., the function, includes seeing (reading) to learn, communication, safe orientation and mobility and performance of tasks within one's environments, etc.

Disability - is the limitation of function experienced by the person having impairment compared with persons of his age and sex who have no parallel impairment.

Handicap - is the disadvantage imposed by impairment and/or disability upon a specific person living within his own cultural context.

A person with impairment is not necessarily disabled or handicapped, but he may be disabled, or handicapped, or both.

Rehabilitation - is the concept and process of a disabled or handicapped person's optimal achievement of self-realization.

This may be through his efforts alone, or with assistance from his family, neighborhood, and/or community.

His potential for rehabilitation lies in the interplay of his problems and the resources available to solve them.

PREFACE

Workers for the "blind and visually handicapped" say that the delivery of their services is obstructed by many barriers:

(1) no professional standards have been established for the examination procedures, instrumentation, and test conditions under which measurements of vision are secured;

(2) the measurements which examiners record are expressed in terms of the results of the specific tests which are administered and have never been correlated through research to the person's visual needs and demonstrated performance;

(3) no standard classification system is in use across the field for the cause of the deficits in vision to supplement the recorded measurements;

(4) no additional information is consistently provided on other aspects of the person's physical and emotional condition, his state of fatigue on the day of the examination, social pressures, etc., which would indicate the need for repeated testing with parallel measurements comparably recorded for the series of dates and times of day, to evidence the fluctuating function under varying conditions;

(5) the measurements are not interpreted for non-clinical personnel responsible for social and vocational training, in terms of the implications for the person's everyday life;

(6) the statutory measurements for "legal blindness" and other groupings of measurements into "ranges" having cut-off points set arbitrarily upon impressions (rather than research) gained from working in the field are not based upon - or indicative of - what a person can or cannot do, or how he is found able to perform activities which the stereotype produced by the clinical measurement is taken to preclude.

The result of these barriers to service is a lack of reliable knowledge on *who*, *how many*, having *what kind* of visual defect and *what* cause, *what* impairment of function for everyday life, and *what* other problems of physical and emotional health, education, employment, or social pressure, might require service if agencies knew *where* the people could be located.

Statutory registers for the "legally blind" are said by workers in the field to be unreliable for statistical purposes and uninformative as a basis for assessing the need of an individual for service and the results of any service given to him.

The fifth (1966) and Sixth (1967) Annual Conferences of the program on Model Reporting Areas for Blindness Statistics, which was set up as an intramural project by the National Institute of Neurological Diseases and Blindness, emphasized participating agencies' confusion over varying terms used by clinicians on medical reports and varying report forms required by federal and state agencies. The major dissatisfaction was the statutory program for certification of "legal blindness," because it was said to cause a detrimental attitude towards the "blind" among community groups whose support was essential for educational and employment services. Moreover, the people so labeled felt themselves stigmatized by the label. Nor did the statutory requirement that only ophthalmologists be authorized to execute the certification result in consistent clinical reports since within this profession the examination procedures, instrumentation, and environmental test conditions had not been standardized.

The need was expressed for development, adoption, and consistent use of standard practices as well as consistent terminology and measurements for the records. Further, some assurance of the additional information needed on a person's experience and performance level for everyday activities in his family, neighborhood, and community life would provide to service agencies the basis for evaluation of his needs. Thus, when the services and his performance had been followed over a period of time and documented consistently, the effectiveness of the program could be evaluated in terms of his improvement towards independence. And if the performance of persons whose vision was examined by standardized procedures was pooled it might then be seen what range of activities was related to a stated range of measured vision, and cut-off points could be established which would be related accurately and realistically to the use of vision for specific tasks, hence to the services needed when impairment is found. The result would be a valid base for effective legislation to replace the existing program for certification of "legal blindness."

The Rehabilitation Codes project in 1958 approached these barriers to service by appointing a working committee to restudy the existing practices of examining, measuring, classifying, and recording vision. The purpose was formulation of standards to be recommended to the examining professions and workers for the "blind and visually handicapped." The committee was asked to derive from these standards, within the pattern established for an overall Impairment Code, a rationale for differentiating between "vision" and "visual function" as a human function of "seeing." The aim was the description of impaired visual function.

This committee work was funded from 1958 to 1964 by the Association for the Aid of Crippled Children, the Easter Seal Foundation, and the federal Office of Vocational Rehabilitation, and from 1964 to May 31, 1968 under a research grant from the National Institute of Neurological Diseases and Blindness, of the National Institutes of Health. This final report is for the NINDB research grant program which continued the initial committee's work.

CLASSIFICATION OF IMPAIRMENT OF VISUAL FUNCTION

Final Report
1965-1968

Background

This research program resulted from a four-year study to develop a classification for impairment of visual function differentiated from defects of vision. The study had been carried out by the Subcommittee on Impairment of Visual Function, of the Rehabilitation Codes project, which started in 1957 under sponsorship by the Association for the Aid of Crippled Children co-financed with the federal Office of Vocational Rehabilitation and the Easter Seal Foundation.

The Rehabilitation Codes project undertook to develop a body of classifications of information which rehabilitation agency personnel stated they lacked about the rehabilitant in his personal, family, and community context. Usually having only diagnostic or employment details they felt unable to evaluate his unimpaired assets, his education and past experience, and his potential for a future independent life. The attitudes of his family, friends, and community acquaintances were known to be critical factors in building or tearing down his morale and motivation.

These needs were expressed in the first year's field work of the project when the Principal Investigator interviewed several hundred agency staff members in their programs across the country. Three additional problems were said to hamper effective delivery of service. These were:

> the voluminous and time-consuming case records,
>
> the various professional jargons which impeded communication among the different types of workers drawn from many disciplinary backgrounds, and
>
> the lack of any means of measuring the results of the services in terms of changes in the recipient's status throughout the rehabilitation process.

These expressed needs were the basis for the structure of the Rehabilitation Codes classifications of information and for their incorporation in a longitudinal records system. The intention was to provide a consistent vocabulary of descriptive phrases applicable to a full range of a person's function and experience over the span of time required for services to help establish him in a satisfying independent daily life. The vocabulary would constitute a common language for use by the many professional, community, and personal contacts of the person receiving services, mutually understood and interpreted at whatever date the records might be consulted, and equally understood by him and his family.

Prior to the project's initiation a number of professional personnel in the Borough of Queens of New York City had discussed their problems of inter-agency communication with family physicians and children's parents. The physicians said they lacked the vocabulary to interpret clinical findings to families; they could not establish priorities in a long-range program of medical, educational, social, and other services as indicated in hospital clinic reports on young children who must yet begin to walk and already showed learning problems.

During 1955-56 representatives of some national agencies had become interested in the Queens discussions. Among them was the Chairman of the Subcommittee on the Physical Impairment Code, of the USPHS Surgeon General's National Committee on Vital and Health Statistics. When the code project was funded he continued to serve on its Advisory Committee and until 1968. Early in 1958 the USPHS Subcommittee invited the project's Principal Investigator to serve, and then found that with the Chairman and a representative from the Social Security Administration they had three members in common with the project. The Subcommittee proposed to suspend work turning over further code developments to the Rehabilitation Codes project with the three maintaining liaison between the two groups. They would resume deliberations when the project had produced a completed code draft for impairment.

On study, the project committee found the Subcommittee's 1955 code draft to consist of a variety of injury and disease entities, missing parts of the anatomy, and--in the case of vision--the statutory measurements for "legal blindness." These diagnoses reflected current practices of identifying "the problem" and labeling the person who might have it, but in rehabilitation they were of little help in evaluating the effects upon a person's daily life. Nor were the entries amenable to consistent description reflecting the changes in status from one date to another evaluation date.

A person certified as "legally blind" might be less disabled than one with slightly higher residual vision who could not meet the statutory requirement but who would not be eligible for the services provided under the statutory program. A young adult blinded after completing college and a few years' employment would face different problems of adjustment from those of a young adult blind from birth. The latter's entire learning process would have been grossly limited without the unimpaired sensory stimulus common to unimpaired children, yet his statutory measurement and certification would imply that his problems were the same as those of the college graduate. The effect of the Statutory program was to produce a stereotype of "the blind" as a group of identical people although their one common element might be only that statutory measurement. This negation of human variability and individuality could form no basis for a rehabilitation program.

The 1955 draft of the Surgeon General's Impairment Code provided only five entries with a maximum of ten and used the statutory measurements as a definition of "blindness" with other cut-off points for "defective vision." These are shown on the next pages, along with the overall list of Impairment Code headings, and the Subcommittee membership:

Subcommittee on the Physical Impairment Code
Surgeon General's National Committee on Vital and Health Statistics
USPHS

PROPOSED PHYSICAL AND MENTAL IMPAIRMENT CODE (1955 draft)

Absence of or Loss of Part of Body (001-099)

001-059	Extremities
060-079	Organs
080-099	Bones and Parts NEC

Impairment of Movement, Musculoskeletal System (011-299)

100-149	Ankylosis
150-179	Instability of Joint
180-199	Flail Joint

200-249	Contracture or Shortening of muscles and/or tendons
250-299	Limitation of motion, joint NEC

Impairment of Special Senses and Speech Defects (300-339)

300-309	Blindness
310-319	Deafness
320-329	Impairment of Special Senses NEC
330-339	Speech defects

Impairment of Nervous System NEC (400-449)

400-449	Paralysis
450-459	Convulsive Disorders
460-469	Chronic disease or impairment of nervous system NEC

Chronic Brain Disorders with Associated Structural Changes in the Brain, or of Other Demonstrable Etiology (500-509)

500-	Psychosis
505-	Psychoneurosis
509	Mental disorders NEC

Psychogenic Disorders and Mental Deficiency (510-559)

510-519	Psychosis
520-539	Psychoneurotic disorders
540-549	Personality and behavior disorders
550-559	Mental Deficiency

Impairment due to Chronic Disease NEC (600-739)

600-619	Special diseases
620-639	Circulatory system
640-649	Respiratory system
650-669	Digestive system
670-689	Urogenital system
690-699	Skin and cellular tissue
700-709	Musculoskeletal system
710-719	Endocrine system
720-	Blood and blood forming organs
730-	Body generally
-739	Chronic disease NEC

Deformity and Impairment NEC (800-999)

800-829	Nonunion or malunion of bone
830-839	Shortening of extremity
840-859	Artificial orifice or valve
860-899	Disfigurement and deformity NEC
900-999	Impairment NEC

(NEC = not elsewhere covered)

A PROPOSED SYSTEM FOR CODING PHYSICAL AND MENTAL IMPAIRMENTS

Prepared by

Subcommittee on the Physical Impairment Code
U. S. National Committee on Vital and Health Statistics

1955

IMPAIRMENT OF SPECIAL SENSES AND SPEECH DEFECTS (300-339)

Blindness (Includes absence of eye) (300-309)

Blindness: With correction, visual acuity not better than 20/200 or limitation in visual field subtending an angular distance no greater than 20 degrees.

Defective Vision: With correction, visual acuity not better than 20/60 but better than 20/200, or an equivalent limitation in the visual field.

300 Blindness, both eyes

301 Blindness, one eye; defective vision other eye

302 Blindness, one eye; normal vision other eye

303 Defective vision NEC

309 Eye conditions (Use this code for cases which cannot be classified in codes 300-303, e.g., color blindness, ptosis of eyelid, etc.)

(NEC = not elsewhere covered)

SUBCOMMITTEES AND AD HOC COMMITTEES OF THE UNITED STATES NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

Classification of Physical Impairments

Appointment - February 1951

Assignment - To determine current practices in coding physical impairments and the type of classification needs for statistical studies of data from hospitals, clinics, disability plans, and public health programs.

Members - Eugene L. Hamilton, Chief, Medical Statistics Division, Office of the Surgeon General, Department of the Army, Washington, D.C. Chairman.

- Selwyn D. Collins, Ph.D., Chief, Morbidity and Health Statistics Branch, Division of Public Health Methods, Public Health Service, Department of Health, Education, and Welfare, Washington, D.C.
- Henry H. Kessler, M.D., Newark, N.J.
- Aaron Krute, Bureau of Old Age and Survivors Insurance, Social Security Administration, Department of Health, Education, and Welfare, Baltimore, Md.
- Marjorie E. Moore, Ph.D., Chief, Division of Research and Special Studies, Office of Vocational Rehabilitation, Department of Health, Education, and Welfare, Washington, D.C.
- Maya Riviere, D. Phil. (Oxon.), Project Associate, Association for the Aid of Crippled Children, New York, N.Y.
- Barkev Sanders, Ph.D., Chief, Community Research in Public Health Practice, Public Health Service, Department of Health, Education, and Welfare, Washington, D.C.

(From the Annual Report of the United States National Committee on Vital and Health Statistics - Fiscal Year 1958)

By the date of the Surgeon General's Subcommittee proposal that they take over the Impairment Code work, the Rehabilitation Codes Advisory Committee had already established terms of reference for their work, defining "rehabilitation," "impairment," "disability," and "handicap." The definitions would express the context within which the descriptions for the person would develope. But the 1955 draft of the Surgeon General's Impairment Code was just the kind of labeling which the project intended to jettison, in desiring to reorient professional attitudes and service towards individualized evaluation of the person as a human being, rather than the possessor of some detrimental condition. The Advisory Committee accepted the proposal to undertake the Impairment Code development in order to secure a draft consistent with the philosophy and pattern for the Rehabilitation Codes.

In order to implement this additional work the Principal Investigator set up working committees of recognized professional specialists, starting with those concerned with sensory dysfunctions and problems of learning and affect. The intention was to appoint new committees as these completed their code sections, until all areas of impairment had been covered. The Subcommittee on Impairment of Visual Function drew twenty-seven people from twenty-four agencies, including ophthalmologists, optometrists, administrators, research and rehabilitation program directors:

SUBCOMMITTEE ON IMPAIRMENT OF VISUAL FUNCTION

June, 1960 - January, 1964

Charles Warren Bledsoe Assistant Chief Division of Services for the Blind Office of Vocational Rehabilitation Department of Health, Education, and Welfare	Reverend Thomas J. Carroll Director Catholic Guild for All the Blind

A. A. Cinotti, M.D.
Assistant Professor Ophthalmology
Seton Hall University Medical School
(and) Director of Resident Training
New York Eye and Ear Hospital

John K. Dupress, Director
Technological Research
Division of Research and Statistics
American Foundation for the Blind

Milton D. Graham, Ph.D., Director
Division of Research and Statistics
American Foundation for the Blind

Kathern F. Gruber, Director
Division of Program Development
American Foundation for the Blind

Elizabeth M. Hatfield, M.PH.
Consultant in Statistics
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Concept of an Impairment Code for Rehabilitation

The focus of the Rehabilitation Codes project was on the individual in his totality as a human being of many capabilities as well as any less adequate resources or diagnosable impairment of function. For this reason any professional or statutory designation of the person by a disease term or numerical measurement (even if this might be "I.Q. 158") was held to be both antithetical and inadequate as a basis for understanding his varied potentials and problems.

Medicine and statutory programs for medical care perpetuated their focus upon pathology and the anatomical deficit, as implied in such phrases as "the amputee" or "the legally blind." This attitude ignored and negated all other consideration of the person having the problem. It denied the availability of any other function, talent, experience, motivation, and family resources. It fixed for all time an identification which might--even after medical treatment--turn out to be a correctible or self-limiting condition: the label was not then altered to reflect the improved or altered level of function. "Once a TB, always a TB."

For the Rehabilitation Codes it would be necessary to conceive of an Impairment Code developed within the context of the human being's entire range of function--from all possible function to absence of all function.

From initial contact to each subsequent evaluation date, through to final contact, even a disease process may change in status, requiring descriptions relevant at each date. In rehabilitation the person's use of his functions with prostheses and aids, or while maintaining a regimen of prescribed diet and insulin, or when recovered from an acute febrile state, will be different from the original diagnosis and will signify response possibly to some service. For this reason, descriptions reflecting the person's response to service are required as varying aspects of any range of descriptions for one aspect of function. Without this range of information, comparable records for a series of dates throughout the period of service cannot be maintained.

It is the comparability of status at pinpointed dates which provides the measuring rods for the effectiveness of the service provided and the person's ability to utilize the service. To date of this project no such measurement had been attempted by the traditional methods of case recording. Masses of statistics quantifying (mainly) aspects of the professional service of administrative agency were produced regularly, but little information was forthcoming on the quality of the service in terms of the end results for the recipient person.

The project working committees therefore must first define what unimpaired function can be expected to include--not the so-called "normal" function--since in a roomful of twenty persons all wearing various kinds of prescription lenses, the norm obviously is a diagnosed amount of impaired vision.

The "ingredients" of unimpaired visual function would provide the details which could be described for various kinds of impairment following the pattern of descriptions established for the Rehabilitation Codes Impairment Code: absence, measurable limitation, and aberration (differing in quality, as implied by intermittency or distortion) of function.

But a further differentiation was held to be even more basic, in that the organic or anatomical function was not accepted as the totality of human function, anymore than was the label of a disease. "Vision" was different from the human visual function of "seeing." "Seeing" involves the use of the anatomical structures. Similarly, measurement of vision (and of deficits of that sense) are not the same as descriptions of impairment of seeing.

All these concepts and terms must be defined by each working subcommittee for the various areas of impairment. The period of defining unimpaired (human) function and of delimiting the field of study constituted the most difficult for each committee because here the divergent approaches of disciplines clashed and must be reconciled for a synthesis of approach to the human being as the focus for service.

This subcommittee met from June, 1960 to June, 1963 in a total of seventeen all-day work sessions, with numerous smaller group meetings on assigned tasks in between. Their services to the project were contributed personally by some members and by their agencies for others.

From the earliest subcommittee meetings the divergence of approach was clearly marked for the members concerned with diagnosis and clinical treatment services and for those concerned with direct services for rehabilitation. Considerable time was spent in attempting to reconcile these emphases within the concepts and definitions of the Rehabilitation Codes project.

Clinicians thought that the diagnostic label was adequate for their purposes and could be interpreted by service personnel without further elucidation on their part: for them the diagnosed condition was the impairment, while for the rehabilitation minded, the diagnosis most often was the pathological cause of the limited human function of "seeing." Moreover, the effects for a specific person could not be reliably deduced from the category "legally blind," and other similar labels contributed little to the help needed by persons having "partial sight."

A further problem in interpreting the medical report was the lack of consistency of clinical examination techniques, equipment, and testing conditions. Such variations as testing at twenty feet and then moving the test object and person closer together to achieve a different test result was not recorded: this was the kind of information which rehabilitation agencies would find useful in adapting reading and work conditions for various partially sighted rehabilitants.

In an effort to bring the two factions together, it was agreed to lay down some recommendations for standard examination, equipment, and test conditions such as lighting, color and size of test object, etc., and to spell out some of the numerical measurement about which clinicians disagreed among themselves. The resulting code was titled "Measurement of Vision" with the question of differentiating description of visual function, or the uses of vision, still undecided. Each code section was supplemented by a page of instructions and definitions.

Dry-Run Test of the Code for Measurement of Vision

In August, 1963, the facilities of the Catholic Guild for All the Blind were offered for a dry-run test on using the Measurements Code. A manual of instructions and a prepared record form for the use of examiners were developed.

An attempt would be made to code and record the findings of the examination. Case material to be used during the test was offered by Richard E. Hoover, M.D., a Subcommittee member. The records chosen illustrated a variety of problems needing more information than the usual diagnosis or certification measurements report provides.

The Catholic Guild for All the Blind organized a two-day conference in which the invited participants reflected the interest of service agencies in securing information on residual function. The conference was titled "Problems Involved in Delineation of Function Levels in Persons with Diagnosed Low Vision."

The purpose was to have the participants try to describe what a person with a stated diagnosis might be expected to perform safely, relying upon his residual visual function alone, then what he might also do, taking into account his unimpaired mentality, motivation, education, and experience, as well as by means of clues received from his other unimpaired senses.

The hitherto unanswered question of concern was "how did one person manage to carry out activities which another with the same diagnosis was unable to do?" To test the code, the question was whether varying test procedures, equipment, and conditions resulted in valid findings, or whether some improvement in determining residual function might be ascertained by adhering to and recording variations in standardized procedures, equipment, and test conditions. Could other standards be identified than those here recommended which would improve examiners' findings? Would adoption of prepared record forms and terminology for examiners' reports to rehabilitation agencies improve the latters' quality of service to the visually impaired?

Of special interest to the participants was information on the label of "legally blind" as it affected the kind of service provided in quantity or quality and as it might be shown to limit the productive independent life of the person so labeled, or to assist him through the statutory service.

During the two days the participants accomplished a revision of the materials submitted and recommended that certain additional details be developed for inclusion in the examination. Recording of findings for near vision without a statement of the distance at which each reading was made was agreed to be useless. Grouping a range of visual sensitivity for fractional readings of distance and near vision (example: 20/320-20/125 or 20/1000-20/400) was agreed to be unsatisfactory because one point above or below the two extremes of each range would throw the person into another, which under Social Security, Veterans Administration, and Workmen's Compensation programs would affect his legal status. The exact reading should be recorded. Then the information shared by all agencies would be consistent. The "burden of the proof" should be placed upon the examiner, for whom the instruction specified that a reading be placed in the worser range, if ranges alone were to be recorded. Only when sufficient information had been accumulated to indicate the arbitrariness of the statutory measurement and designation as "legally blind" would it be possible to draft new legislation related to the modern concept of residual visual function and services provided under special programs for rehabilitation.

The participants expressed approval of the project's attempt to re-orient the measurements towards improved benefits for the person with visual problems. They recommended that specific research proposals be developed to ascertain how well a person can perform using only his visual sense, without other sensory clues, unusual intelligence, experience, and motivation. Considerable discussion occurred regarding the kind of test objects currently in use on the assumption that the person examined has a specific cultural and educational background.

Additional areas of needed research were the use of sensory stimuli, memory patterns, and various personal factors which might exert influence upon performance. Meanwhile, the need for immediate consistent descriptions of the function which a particular person exhibits related to his measurements of vision might be studied along the lines of what it was safe for him to try to do, what was not useful residual vision for daily tasks in his accustomed environment, what function was marginally useful, and what was more than marginally useful but still outside the range of the statistical norm.

The saving in a prepared record form for examiners' use was found to be favorably influential in securing their agreement to follow recommended procedures. It would lend itself to collection of comparable data more readily than the narrative case reports which require time to peruse and excerpt and which are not comparable within one person's record for details recorded from one to another date, much less so from one person's to another person's records.

These and other recommendations for the Measurements Code revisions and for further development of a code for impairment of visual function were referred by conference participants* to the project Subcommittee on Impairment of Visual Function. Revisions proceeded in the Subcommittee for the balance of 1963 when the group as a whole accepted the Measurements Code as a more useful statement of defects of vision, with the derived code for impairment of visual function next to be developed.

WORKSHOP ON PROBLEMS INVOLVED IN DELINEATION OF FUNCTION LEVELS IN PERSONS WITH DIAGNOSED LOW VISION

Newton, Mass.
August 14-15, 1963
Sponsored by The Rehabilitation Codes and The Catholic Guild
for All the Blind, Newton, Mass.

Rev. Thomas J. Carroll, Chairman
Director, The Catholic Guild for All the Blind

Robert Amendola, Instructor, St. Paul's Rehabilitation Center
The Catholic Guild for All the Blind

Fr. Robert Carolan, Director of Professional Services
The Catholic Guild for All the Blind

Serena Cummings
Division of Special Education, Massachusetts Department of Education

John K. Dupress, Director, Technological Research
Division of Research and Statistics
American Foundation for the Blind

Frederick Greenhan, Director of Rehabilitation
Department of Education, Massachusetts Division of the Blind

Kathern F. Gruber, Director, Division of Program Development
American Foundation for the Blind

Richard E. Hoover, M.D., Chief of Staff
Presbyterian Eye, Ear, Nose, and Throat Charity Hospital, Baltimore, and
Instructor in Ophthalmology, The Johns Hopkins Medical Institutions

Mary McLaughlin, Supervisor of Children's Services
Department of Education, Massachusetts Division of the Blind

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*List of conference participants on this page and the following page.

Juozas Mickunas, Jr., Experimental Psychologist
Bio-Dynamics, Inc.

Leo H. Riley, M.D., Director of Research, American Center for Research in Blindness and Rehabilitation

Maya Riviere, D. Phil. (Oxon.), Principal Investigator, The Rehabilitation Codes

Frederick A. Silver, Chief, Mobility Department, St. Paul's Rehabilitation Center, The Catholic Guild for All the Blind

Alfred J. Therrien, Blinded Veterans Association

Change of Sponsorship for the Rehabilitation Codes Project

In March, 1964 sponsorship of the Rehabilitation Codes project by the Association for the Aid to Crippled Children came to an end with a change in agency policy.

Several members of the project Advisory Committee and the working subcommittees agreed to serve as Trustees for a new sponsoring agency to continue the administration.

The decision to continue was based immediately upon the existence of a four-year grant program for the work of the Subcommittee on Communicative Disorders, which had proceeded more rapidly than had that of the Subcommittee on Impairment of Visual Function. The grant had been approved from 1963 by the National Institute of Neurological Diseases and Blindness of the USPHS National Institutes of Health, after they had funded two national conferences on the code draft for communicative disorders. The first had been held in 1961 in Bethesda, Maryland, the second--on Impairment of Language Function--in late 1963 in Carmel, California. Formal reports had already been published.

After considerable discussion with NINDB prior to incorporation, the Trustees approved a program for a series of grant applications on various areas of impairment to complete the draft for submission to the Surgeon General's Subcommittee. The pattern of the Communicative Disorders code was the model.

The Rehabilitation Codes, Inc. Program on Impairment of Visual Function

Starting April, 1964 the new corporation came into existence under New York State law as a non-profit educational and research organization. The Easter Seal Foundation allowed the residue of the grant to the former sponsor to be transferred to the corporation, and the necessary steps were taken for the existing NINDB grant to be transferred for the Communicative Disorders program.

Both subcommittees of the earlier project on areas of communicative disorders and on impairment of visual function were reviewed as the basis for continuing work, and a number of members were invited to serve the corporation, along with new members to be recruited as work progressed.

Program on Impairment of Visual Function

Work started immediately on a grant application under a new program advisory committee consisting of

Richard E. Hoover, M.D., Instructor in Ophthalmology,
The Johns Hopkins Medical Institutions

P. J. Leinfelder, Sr., M.D., Professor of Ophthalmology,
College of Medicine, The University of Iowa

Maurice Poster, O.D., Chairman, Committee on Contact Lenses,
American Optometric Association

Leo H. Riley, M.D., Research Director, American Center for
Research in Blindness and Rehabilitation

Roy O. Scholz, M.D., Assistant Professor in Ophthalmology,
The Johns Hopkins University

Dr. Leinfelder agreed to serve as Chairman of this Planning Committee. He had been recruited for the earlier Subcommittee by Dr. Hoover from the Committee on Defining Blindness which NINDB had set up for its own purposes. The Principal Investigator continued in the same capacity as for the original Rehabilitation Codes project.

The grant application was approved to start June, 1965, and the Planning Committee began work following the recommendations of the Newton Workshop participants. The manual containing the Measurements Code and text was revised.

Following suggestions of the participants of a Site Visit from NINDB in February, 1965 when the application was under consideration, plans to hold a conference of specialists from a variety of allied disciplines were discussed. The purpose was to secure expert study of the program premises, and recommendations for the development of the code on impairment of visual function.

Planning the Conference

A preliminary meeting was held on February 4, 1966 by the Program Advisory Committee and Principal Investigator with four invited specialists in industrial ophthalmology, low vision, and problems of color vision defects. They reviewed the manual revisions and discussed the choice of participants for the conference on vision and visual performance. The program representatives were Dr. Leinfelder, Chairman, Dr. Hoover, Dr. Poster, Dr. Scholz, and Dr. Riviere, Principal Investigator. The four guests were

Paul Boeder, M.D.: Department of Ophthalmology, University Hospitals, University of Iowa

John W. Henderson, M.D.: Department of Ophthalmic Surgery, University Hospital, The University of Michigan Medical Center

Joseph F. Novak, M.D.: 520 Medical Arts Building, Pittsburgh, Pennsylvania

Melvin L. Rubin, M.D.: Department of Ophthalmology, College of Medicine, The University of Florida

The continuing question as to whether clinicians would accept a differentiation between the sense of vision and the function of "seeing" was again brought forth. Since statements on defects of vision as an organic problem were the basis for the Measurements Code, and the intention of the Impairment Code was to show dysfunction in the human use of the sense, it was necessary to secure firm advice in order to approach the grant program work. The group agreed on a strong statement that measurements do not directly imply the impairment of human function or the resulting disability which may be found on attempting to provide rehabilitation. They accepted the differentiation of the Rehabilitation Codes definitions for "impairment," "disability," and "handicap." They studied and concluded that the Impairment Code pattern for the Communicative Disorders section was valid for rehabilitation needs and a useful model for impairment of visual function. The classifications would be "absence" of function, "measurable limitation" of function, and those--to date--unmeasurable aberrations or dysfunctions which might be described as "distortions" or as "intermittent" (etc.) function. They stressed the need for examiners to be in a position of responsibility to interpret the implications of their clinical findings for rehabilitation personnel. They felt that the Impairment Code would have a beneficial effect of reorienting current and especially the younger incoming practitioners in the clinical field.

In discussing the NINDB proposal for a national conference the participants recommended that conference guests be drawn largely from fields of services connected directly with residual function rather than programs for the blind. It would be useful for members of the Rehabilitation Codes working committee on Communicative Disorders to be present to present their rationale and working methods which resulted in the code section which was to be followed as a model.

Their examination of the manual instructions for examination and measurement of vision found that a useful protocol had been developed. Closer liaison between examiners and staff of direct service agencies would improve the quality of both by improving the inter-professional communication and understanding. To diagnose without providing the interpretation required to implement rehabilitation was no help to the person whose function as a human being was limited by visual defect.

Finally, they made several further revisions in the manual material and recommended that a field test be organized with special attention to the adaptations of the measurements and examination procedures and equipment to search carefully for any possible residual function. Some of the methods suggested included varying the distances between patient and test object, a wider range of visual aids, the use of larger print, and color clues.

Field Tests, May, 1966

In preparation for the conference scheduled for June, 1966 the Planning Committee organized three field tests. These are reported on under the following headings:

(1) the field test report to the project Planning Committee by the Principal Investigator,

(2) the protocol prepared for the Examiners' guidance in carrying out the field tests,

(3) the Examiners' critiques on their experience using the field test materials: manual of instructions, the Measurements Code, and the recording procedures.

Principal Investigator's Report to the Planning Committee

The cooperation of three direct service programs was secured for the purpose of conducting field tests of the Measurements Code during May, 1966. The manual submitted to their clinical designates consisted of a code for measurement of various aspects of vision, and a body of recommended testing conditions, instrumentation, and examination procedures, with a prepared record form on which the findings, the test conditions, instrumentation, procedures, and any variants from those recommended, were to be written for each person examined. The cooperating agencies were

1. Boston University, Department of Ophthalmology,
   Ephraim Friedman, M.D., Chief
   - Designated Examiner: Theodore A. Stamas, M.D.

2. Greater Baltimore Medical Center, Department of Ophthalmology,
   Richard E. Hoover, M.D., Chief
   - Designated Examiner: Gregory Sophocleus, M.D.
     Chief Resident

3. Optometric Center of New York, Maurice G. Poster, O.D.,
   President, Professional Advisory Board
   - Designated Examiners: Donald Gelfer, O.D. and
     George Obsuth, O.D., Staff Members

Thirty-nine people were examined in the field test. Their demographic information was recorded on prepared interview forms by the Principal Investigator, either from records on file or during personal interview. Each person was asked to discuss how he coped with daily activities for self-care (personal hygiene, bathing, dressing, getting around the house and neighborhood, moving in the community, etc.) and for home activities (shopping, home-making and child care, etc.) using the standard checklists developed for the Rehabilitation Codes. Each activity was rated on a ten-point scale for the degree of independence which the person said he had. Expressions of opinion as to the services needs and received were elicited, including certification as a "legally blind" person.

All of the Boston University test subjects were "legally blind" except two, both of whom had low vision and other problems which broadened the opportunity for examination. The examiner showed a considerable amount of interest and attention in varying the test conditions and procedures to suit each person's vision, especially for the two not certified, one of whom had a scotoma difficult to plot. Ages of subjects ranged from 22 to 76 years, and the number whose loss resulted from neglected detached retinas was high. The great variation of activities possible to some of the certified reflected in proportion their date of onset, past education and experience, morale, and general health at the date of examination.

In the second test all of the people examined were younger adult employees of the cooperating agency, who were offered routine examinations and had not previously been known to have any defects of vision. They provided a wider range of less severe, minimal, or no defects, except for two, who could have been certified as "legally blind" on the basis of hitherto unreported vision deficits. One, accustomed to wear contact lenses at work, was head nurse on a ward in the Medical Center: Dr. Hoover subsequently followed up another family member because of her defect being a ring scotoma and found a brother with the same condition, also employed satisfactorily by the Medical Center. Ages ranged 20-53 years.

The third test was also of younger patients, none over 26 years of age, of whom three were 9, 13, and 13 years. The Optometric Center is particularly concerned with the school-age population and with even younger children having problems of developing visual function.

Most of the first and older group had been recently blinded after prolonged visual problems and systemic disease, while in the other two younger groups the diagnosis of refractive errors and limitations of field indicated the value of early identification for prevention of later severer impairment. The less vision a person had, the shorter time it took for his entire examination, while the ring and central scotomas found in two people required the longest examination time. Routine procedures did not map out the extent or location of pattern. The examiners recommended that the Manual of Instructions expand the text on how to test adequately and how to outline the pattern on the tangent screen.

For each person examined the amount of time required and to record the findings was clocked by the Principal Investigator. It took the examiners up to the fifth examination to become sufficiently familiar with the new protocol to achieve what each stated was his "routine" performance. When this had been reached each examiner remarked that the remaining examinations and the recording took no longer than he would have spent on just examining, without being sure he would have included testing for color vision and without having recorded the findings or written up his case notes, hence the new protocol saved him time for a more complete result, using the prepared record form. A summary shows in minutes the actual and average times for the entire protocol in the three tests:

Test No.	No. of Patients	Aver. For Group	Examination Time Only	Exam. Aver.	Record Only	Record Aver.
1	20	51 min.	5- 90 min.	38 min.	4-34 min.	13 min.
2	10	67	35-100	62	2-10	5
3	9	45	30- 60	39	4-20	6

The group in the first test were severely impaired. Loss of one eye or of both eyes obviously produced a kind of bias in regard to the shorter average time required for the examination and coding protocol, while for the two groups with half as many patients each, the greater amount of vision present necessitated considerably more time for every detail of the protocol to be followed. These biases for the small number of patients examined were further influenced by the extreme care of the examiner in the first test in determining localization of light and two-light discrimination. Any perception of light would be of great importance to the future rehabilitation training of such severely impaired persons. Examination of field was the next most time-consuming area, and the two scotoma defects discovered were the kind of fluke which must indicate the need in field tests for a sufficiently large number of subjects to produce any valid statistical material.

On completion of each test session the examiner undertook to write a critique of the test materials and protocol. Inevitably all three reported some parallel experiences and opinions. Similar adaptations of the examination procedures were made, and each examiner exhibited an interest in experimentation to investigate in a variety of ways when the first few tries were unproductive: this enthusiasm contradicted some pessimistic forecasts contributed in earlier pre-project discussions with a variety of persons interviewed preparatory to submitting an application for funding by any government agency. Contrary to defeatist prognostications, all three examiners took in their stride a need to change routine, to experiment, to try a new protocol, and to spend more than average time with any patient having a provocative condition, as well as to learn the newly recommended procedures, the rationale for the altered terms and test requirements, the coding instructions, and a pre-coded record form, and even to enquire about the final test results.

To the Principal Investigator, the most striking test result was the opportunity to compare the progress made by eighteen* of the legally blind persons by the twelfth week of their rehabilitation process, which was the date at which they were interviewed and examined in the field test. The variety and extent of residual vision and visual function documented for the eighteen illuminated the critical need for individual assessment if the proposed training for personal independence and eventual employment is to have a valid base. Experience at other agencies indicated that this individualized assessment is not a practice in the programs which carry out examination and certification for legal blindness. Neither is it a requirement by any of the identified third-party agencies which purchase service given for people with visual impairment from the three agencies cooperating in the field tests: no evaluation by the paying agency is made of the results of the service for the rehabilitant before the service agency's bill is paid.

Each person participating in the field tests had the purposes explained by both his own agency's representative and by the Principal Investigator, who questioned each person's understanding of his involvement and then secured his written permission on a form prepared in accordance with the Federal funding agency's requirements on the use of human subjects in research programs. Signing the permission form gave further evidence of the person's use of residual visual function or his having learned how to write on a stipulated line during his rehabilitation training.

None of the field test materials was discussed in advance with the examiners since a major aspect of the trial was to see how readily each could assimilate the instructions and principles of the protocol, record form, the instructions on examination procedures, instrumentation, and conditions, as well as the selection of code entries to describe the findings and the recording of information in the prepared spaces of the form.

After each field test the supervising chief of the test agency department reviewed the test findings and the examiner's critique. All test materials were then sent to the Rehabilitation Codes committee for study. This led to the revised material which was submitted to the participants of the June, 1966 conference.

The test materials for the examiner's protocol and the record form are shown on the next two pages.

A summary of the examiners' critiques follows with the recommendations for further revisions or changes. It does not include all the detail submitted, because this would require reference to a specific code instruction or code entry for a full understanding, but the implications of all criticisms are given in more general terms.

Subsequent revisions based on the critiques were further reviewed by two of the examiners, one of whom agreed to participate in the June, 1966 conference and to present information on his test experience.

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*The two persons not included were mentioned above as those having problems of low vision or other aberrations who were examined in the first test but not among those certified as legally blind: actually, both were staff members of the rehabilitation program and had not been known to have any visual defect.

Classification of Impairment
of Visual Function
P. J. Leinfelder, M.D.
Chairman

REHABILITATION CODES, INC.
1860 Broadway, New York, N.Y. 10023
Telephone: 247-1475
Maya Riviere, D.Phil.(Oxon.), Executive Director

May 1966

Protocol for Field Test of the Measurements Code

1. Permission is to be secured in writing from each individual examined or from the responsible adult prior to the examination. The form for this purpose will be provided by the test agency to the examining agency.

2. Access to case records for review of previously recorded examinations and to patients for interviews regarding functions which they can, cannot, or can perform only with certain aids or human assistance shall be scheduled for the Principal Investigator prior to each examination.

3. Procedures in the instructions shall be followed first, where found to be possible; where ineffective they are to be replaced with required adaptations (such as moving the patient or test object nearer) and the adaptations shall be recorded as recommended because of the special problems presented.

4. The time required to examine and to code the findings shall be recorded separately on the coding form in minutes, in serial order from the first to the last patient examined.

5. Examinations will be paid for by The Rehabilitation Codes, Inc., from the NB-05398 grant from the National Institute of Neurological Diseases and Blindness, at a fee-for-service rate to be determined and agreed upon between the test agency and the examining agency.

6. All clinical forms used in the test are to be attached to the coding form for each patient and returned to the test agency by the examining agency.

7. The field test must be completed by May 31, 1966 and the reports with coding forms returned by June 10th, for use in the June Workshop.

8. Where possible the examiner shall participate in the June Workshop in order to make his experience available to the participants in their deliberations.

EXAMINING AGENCY (signed by)____________________ (title)____________

TEST AGENCY (signed by)____________________ (title) Principal Investigator

Fee: $______

Planning Committee

Richard E. Hoover, M.D., Instructor in Ophthalmology, Johns Hopking School of Medicine; Maurice Poster, O.D., Committee on Contact Lenses, American Optometric Association; P. J. Leinfelder, M.D., Professor, Ophthalmology, University of Iowa, College of Medicine; Leo Riley, M.D., Research Director, American Center for Research in Blindness and Rehabilitation, Catholic Guild for All the Blind; Roy O. Scholz, M.D., Assistant Professor in Ophthalmology, Johns Hopkins University

Field Test # __ __ Initials __ __ __ Age at admission __ __ Birthdate __ __ __ __ __ __
"Legally blind": Yes___ No___ Referral agency report __ Date __ __ __ __ __ __
Examination findings ________________________________ Date __ __ __ __ __ __
Most recent examination ________________________________ Date __ __ __ __ __ __

FIELD TEST: MEASUREMENTS examination min. ___ coding min. ___ Date __ __ __ __ __ __

Central Function		uncorrected	code	corrected	code	test object	at distance	adaptations
distance	right	/						
	left	/						
	both	/						
near	right	/						
	left	/						
	both	/						

Peripheral Function		degrees	code		
perimeter	right				
	left				
tangent screen	right				
	left				

Mobility	right		code		
	up				
	nasal				
	temporal				
	down				
	left				
	up				
	nasal				
	temporal				
	down				

Binocular Function		uncorrected degrees	uncorrected code	corrected degrees	corrected code	prisms	
onset of diplopia							
fusion	distance						
	near						
phoria horizontal							
	distance						
	near						
vertical							
	distance						
	near						

color vision			test used	
	right			
	left			

Summary

Field Test Examiners' Critiques

General

1. The applicability of the usual examining procedures and measurements to very young children was questioned. The development of "norms" from birth to age 7 was proposed as a further research problem arising out of a standardized Measurements Code, such as that submitted for field testing.

2. Accepting the proposed differentiation between "vision" and "visual function" the Examiners specified that the Impairment Code to be developed on the basis of the Measurements Code should treat "visual function" as a totality of human function, whereas the Measurements Code separates the organic function into various components. Hence in the Impairment Code some of these measured aspects would have to be combined to arrive at an assessment of described human functions, i.e., the Impairment Code could not be expected to follow the Measurements Code detail by detail since the organic and human functions differ.

3. Attention should be called in the instructions to the Measurements Code provision of a full range of statement from unlimited organic performance to and including absence of all organic capability, while the Impairment Code entries obviously would not list any unimpaired human functions.

4. The coding pattern for all the sensory functions should be consistent in descriptive terminology and categorization of types. The accepted pattern for the development of the Impairment Code is that established for communicative disorders by the Rehabilitation Codes Subcommittee on Communicative Disorders for voice, hearing, speech, and language. It is further accepted that vision is also a modality of communication, as are the other senses: tactile, kinesthetic, etc., but that for working purposes it is more practical to organize the code section development by groups of the accustomed disciplines, with useful cross-fertilization from other parallel committees as may seem productive of consistency of approach.

5. The project Planning Committee must decide how such conditions as "ptosis of eyelid, absent or excessive or inadequate tearing or blinking, photophobia, and infectious or inflammatory conditions of the orbital area should be covered, since they may result in problems of "seeing."

6. The definition of "blindness" for the statutory certification and its confinement in the Impairment Code to one entry for no function bilaterally should be clearly reported and repeated.

7. A coding procedure should be provided for the finding "no measurement possible" with an explanation included in the person's case record.

8. The instructions should specify that examiners record adaptation of procedures for measurement of vision, all details of the equipment used, required, or recommended but not available, the size and color of the test object, modification of the amount of light, or use of colored lenses where glare is experienced in glaucoma and cataract, the distance from the person to the test object and whether the object was brought towards the person, or vice versa, etc.

9. All instructions should be reviewed for the possible inclusion of clarifying statements, for example, the fact that for a uniocular person, the possibility of measuring for binocular use, or for impairment of binocular function, obviously, is eliminated: while stating this should not be necessary it would hasten proceeding to the next necessary measurement until examiners are familiar with the new protocol.

10. The record form section on measurement of binocular function might be placed immediately below that for peripheral. "Function" in each heading should read "vision," since it is vision which is being measured. This would differentiate between vision and "visual function." The headings would then read "central vision," "peripheral vision," and "binocular vision." It was suggested that "measurement of binocular vision" as a heading might be replaced by the phrase "measurement of muscle balance."

11. The instructions should include some admonitions for examiners against relying upon a single reading as the definitive measurement: among factors to be considered are:

    - the difference of vision measured in an ideally lighted examining room and outdoors at dusk or in bright sunlight;

    - the variability of response even under standard test conditions owing to the fatigue of both the person and the examiner;

    - the person's use of hearing to reinforce visual stimuli;

    - the desire of the person to please or not to please, in giving a response;

    - the time of day when the examination is held;

    - the person's and the examiner's current emotional state;

    - the uselessness of the examination in meeting the problems of a person with low vision when low vision aids are not included in testing for reading, with a resulting conclusion recorded that "reading is impossible."

Examiners' Recommendations upon Specific Procedures

12. It was recommended that instructions be developed for examination where a person cannot fix upon the test object during tangent screen measurement of field. If a strong light is projected upon the screen, for low vision persons, the light should be turned on and off rather than continuously traveled, along the perimeter, the inability to fix upon the test object is often accompanied by inability to follow the projected light on the screen.

13. In testing central fields, the 1 mm. test object may be unproductive for low vision persons. Instructions should include starting with a larger size, and its size recorded. A fixed chin rest should be specified for the tangent screen procedure at 39 inches or 1 m. from the screen.

14. Persons tested for central vision often are recorded as having a plus- or minus- reading. Instructions should provide for this additional record.

15. In testing binocular vision, provision should be made to record the "near point convergence."

16. Instructions should be developed for measuring the size, shape, and specific location of scotoma on a tangent screen along with procedures for its quantitative measurement and a method of recording the findings.

17. In measurement of binocular vision, the terms "1st grade," and "2nd grade" should be replaced respectively with "simultaneous perception only" and "fusion only" following the definitions specified for this area.

18. The examiners questioned why the table shown for "tangent screen monocular only" for the eight meridians should read "30 degrees" when the standard chart recommendation is "25 degrees." This question was referred to the committee for clarification (it should be 25).

19. It was recommended that in the section on measuring binocular vision, the phrase "onset of diplopia" be replaced with "onset of double vision" and the measurement be expressed on the record form in number of degrees of deficiency, not in the clinicians' usual practice of recording the number of degrees present, from which they argued they had no difficulty, through knowing the number of degrees which should be present, of arriving at the number in any deficit--a computation which was said to confound recipients of the reports who were not clinicians and was now deemed traditional but out of date and contrary to the current attempt to arrive at a code for the exposition of impairment. This reversal would apply also to the recording of deficits in measurement of monocular excursions.

20. It was recommended that vertical phoria for near vision should be tested at 20 degrees and at the "comfortable" rather than "usual" reading position.

21. Where fixation is a problem it was recommended that the Sloan adaptation of four pieces of white tape placed on the tangent screen to outline a central area of empty space be used.

22. In testing color vision caution should be used in attaining the same brilliance for the red and green light sources since the intensity varies, the green being more dense than the red.

23. Notation in the Instructions should be made regarding the qualitative, rather than quantitative, nature of the code section on color vision: methods of measurement have been derived mainly from earlier diagnostic procedures aimed at identification of pathology and at clinical treatment, rather than at the visual function.

24. While the procedure for determining color perception was found generally valid, it would not prove so for some conditions: the Ishihara test requires a field of a certain size and is useless where the field is less. Should colors be projected upon a screen rather than to use red and green only as now is the current procedure? Should not some test for shades be made?

The Annapolis Conference on Impairment of Visual Function
June 15-18, 1966

Fourteen participants at the Annapolis conference included five guests new to the work of the project: four were clinicians and specialists in the uses of vision, and one was a behavioral scientist experienced in group dynamics and in conferences on developing computer systems, who was presented to the conference as having been invited specifically to assist the three-day work sessions in producing the desired impairment code draft. These were:

Richard Feinberg, Ph.D., Federal Aviation Agency

Jack M. Fugate, Ph.D., Director, Low Vision Clinic, School of Optometry, The Ohio State University

Henry W. Hofstetter, Ph.D., Director, Division of Optometry, The Indiana University

Arthur H. Keeney, M.D., D.Sc., Department of Ophthalmology, Wills Eye Hospital, Philadelphia

Robert J. Teare, Ph.D., Human Sciences Research, Inc.

Two participants represented the parallel program on Impairment of Communicative Disorders, having served both as members of the working group which developed the code section and as faculty members of the four regional conferences at which the materials were taught to peer professionals drawn from public, private, and academic institutions. They were:

Thomas H. Fay, Jr., Ph.D., Chief, Communicative Disorders Service, New York Medical College, Center for Chronic Disease

Richard M. Flower, Ph.D., Chief, Audiology and Speech Clinic, The University of California San Francisco Medical Center

The Boston University field test examiner who had agreed to participate was:

Theodore A. Stamas, M.D., Department of Ophthalmology, Boston University School of Medicine

The field test agency which provided the twenty persons examined in the Boston field test was represented by:

Edmund J. Powers, Assistant Administrator, St. Paul's Rehabilitation Center, Catholic Guild for All the Blind

The remaining five participants were four members of the Planning Committee for the project and the Principal Investigator:

P. J. Leinfelder, M.D., Professor, Ophthalmology, The University of Iowa (and) Chairman, Planning Committee

Richard E. Hoover, M.D., Chief, Department of Ophthalmology, Greater Baltimore Medical Center

Maurice G. Poster, O.D., Chairman, Committee on Contact Lenses, American Optometric Association

Roy O. Scholz, M.D., Assistant Professor, Ophthalmology, Johns Hopkins Medical Institutions

Maya Riviere, D.Phil.(Oxon.), Principal Investigator

After a brief orientation session on the basic definitions, aims, and structure of the Rehabilitation Codes program, which was given to provide the context within which the participants were asked to develop a code section on impairment of visual function, the two representatives of the parallel section on communicative disorders presented the rationale of that committee's development of descriptions of impairment of voice function, hearing, language function, and speech function. They differentiated between the organs, the ears, and their function, hearing, which is a bilateral function parallel to seeing, which is the bilateral function of the organs, the eyes. They described the problems encountered by their committee members when asked first to define unimpaired function, accustomed as they were to approaching their work as conditions of pathology. However, when brought back again and again to the consideration of an individual human being they worked their way through to definition of the areas of human function, and then proceeded to develop therefrom the various descriptive code entries for impairment, in terms of absence of function, measurable limitation of function, and those aberrations which they found evidenced in their daily work but were unable to quantify as yet. They further described the regional teaching conferences, which were used not only to acquaint their peers with the program but to secure their reactions to the material, their response to being asked to apply the descriptions to actual case record writing, and their interest in using such interpretations to ease understanding in professional personnel other than those from their own disciplinary backgrounds.

The conference participants then proceeded to familiarize themselves with the Measurements Code and manual of instructions, which had just been field tested and revised. They agreed that measurements were not useful in indicating what the problems might be for the people whose vision was so measured. They perused the impairment code sections for communicative disorders and agreed that impairment of visual function was also a "disorder of communication" equally with the four areas already covered. They found parallels for several areas of visual function and for hearing, such as in measureable acuity, or sharpness of stimulus perceived, and in discrimination among stimuli. There was the same hope for each code section that use of standard examination procedures might lead to improved clinical records and that uses of residual function might be researched and a person's measurements correlated with what he was found able to perform with residual function, and what, with other clues.

They reviewed the project definitions and accepted them. They considered the rationale for development of standards and the Measurements Code for Vision making recommendations for various revisions towards clarity of meaning. They then stated that they found no difficulty in accepting the philosophy of the new approach or the concepts developed for communicative disorders and expressed their readiness to proceed with work to develop the section on impairment of visual function.

In considering the advisability of including such conditions as excessive or inadequate tearing and blinking, they recommended handling these as interferences with the continuity of seeing. If a measurable amount of function limitation could be determined as the result of such interference, the tearing or blinking might be added to the statement of limitation by using whatever entry might be found in the International Classification of Disease as the "case" since the ICDA was already used for both proximal and distal causes on the longitudinal record forms. This would produce the consistent pattern of a three-digit Impairment Code entry with at least one four-digit ICDA cause entry and possibly two. If, on the other hand, a condition such as "tearing" was found in the ICDA it should not be shown in the Impairment Code as an entry.

Solution of this covering for the miscellaneous conditions grouped under one entry in the 1955 Impairment Code draft of the Surgeon General's Subcommittee was referred to the Principal Investigator by the conference participants.

In general discussion which followed on the aspects of unimpaired function from which impairment entries for visual function were to be derived, several participants noticed that developmental problems had not been spelled out in other code sections. To clarify the approach used in establishing a pattern for the code the project representatives detailed further the actual recording procedures which always enter information for a stated date, with the age at that date specified. As a result, the information on visual function entered under a heading of the date and age at that date would indicate whether or not the function was at the level which should be found in that person, hence either above, below, or the norm. The added entry or entries from the ICDA Cause Code would further indicate that any level indicated as impaired at that age would be of a developmental nature.

All information is recorded as of a stated "today." This renders the successive recording at dates following comparable and indicative of trend.

The subject of "visual perceptual disorders" was brought up as an area of function not covered in the committee discussions. More commonly referred to as "reading disabilities" these were not precisely problems of vision but of what happens to the stimuli which are perceived, to make them become meaningful--a process said to go on inside the head which led some professionals to speak of "processing" stimuli.

The two representatives from the Communicative Disorders program then called the conference participants' attention to a section of their work on Impairment of Language Function, where a person's problem in making meaningful use of stimuli perceived, regardless of the modality, had already been covered. If the "process" of making the perceived stimuli meaningful was not working, the "input" would not make sense. For visual stimuli, the resultant impairment would be a problem in learning to "read" i.e., understand the meaning of the perception.

The participants agreed that the area of dysfunction was covered and should remain where it was in the overall Impairment Code structure, following the input of all the sensory stimuli, since "language function" consists of the use of meaningful symbols of all kinds. However, there should at least be an index of commonly used phrases and terms, so that their related coverage in the Impairment Code could be located.

A question was then raised regarding the statutory definition for "legal blindness" and the omission in the project definition of any reference to limited visual field. The participants agreed that the definition formulated as "absence of light perception in both eyes" which would be total impairment, covered any question of perception for the visual field. In common parlance familiar phrases, such as those in the statutory definition, were used so automatically, and intensifiers were unnecessarily felt to be needed (as in the phrases "the whole man," "total health," etc.) that the word "absence" was hardly taken in as implying "total lack of" function. Since one of the aims of the Rehabilitation Codes was to simplify and clarify terms and phraseology, it was both unnecessary and antithetical to the aims to elaborate the definition. The word "blindness" was stated to be not in use as such in the Impairment Code, and the only sense for the Code in which it was to be understood was in the sense of "absence of light perception in both eyes." A person with any light perception in one eye would not be referred to as "blind." This would emphasize the importance of taking into account any residual function found which might be used to help the person. It would require that a more careful clinical examination be made and that rehabilitation, rather than certification as "legally blind," be the focus of public and private programs.

After developing over a hundred Impairment Code entries to replace the five of the Surgeon General's 1955 code draft, the conference participants recommended that another round of field tests be carried out, with a further development of the record form to include the coding of impairment. This would require the examiners not only to measure vision but to interpret their findings in terms of human function: it was here noted that for each area of vision examined there was not one parallel area of impairment, rather several areas of the clinical findings might have to be grouped to arrive at one area of impaired human function, and then they might be regrouped to describe another area of impairment. The findings must be taken in their total effect upon "seeing."

March, 1968 Field Test

The Planning Committee reviewed all previous committee work and field test results in preparation for the recommended field testing of the first draft of the Impairment Code.

The Principal Investigator prepared clean drafts of the revised materials and a new record form adding the space for entry of the impairments under nine classifications, along with the "cause" code from the International Classification of Diseases Adapted, as approved by the American Hospital Association for hospital use and by the Surgeon General.

The organization of the field test was undertaken by the Chairman of the Planning Committee, P. J. Leinfelder, M.D., using subjects at The University of Iowa, each of whom signed written permission for this use, as required by the Federal government regulations. A new protocol for guidance of the examining ophthalmologist was developed, with special attention called to the fact that the five areas of vision to be measured as a basis for describing impairment were then to be related to nine aspects of visual function which might be determined as impaired. Specifically, to describe impairment of binocular function, both measurement of ocular motility and of binocular vision would have to be taken into account. Hence there would not be a parallel single aspect of impairment derived from each area of vision measured.

For the field test the record form* would not be serialized since the contact with each subject would be a single event. Serialization of actual records would however be required within the Rehabilitation Codes system because following the trend in deterioration or improvement, and of the prescribed corrective or prosthetic devices could be possible only where the record showed findings recorded in the same terms for a series of dates when the person might be seen. This serial structure had already been developed to record multiple different impairments, their causes--proximal and distal, and evaluation for residual disability.

The earlier draft of definitions for "vision" and for "visual function" had been strongly influenced by the clinical approach to the work on the Measurements Code, as follows:

> Vision is the sensory reception of visual stimuli.
>
> Visual function implies the reception and recognition of visual stimuli within appropriate environmental limits.

The next approved definition for "visual function" approached a positive statement on the human use of vision in "seeing" and was phrased:

> Visual function implies the sense of vision and its binocular use within appropriate environmental limits.

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*See page 125.

This statement was modified to emphasize the "use" element and was finally adopted for the project:

> Visual function implies the binocular use of the sense of vision within appropriate environmental limits.

The Planning Committee was now faced with presenting for field testing an Impairment Code draft--as developed at the Annapolis Conference--which had moved closer to the desired descriptions on impairment of "seeing" but which still reflected strongly the clinical findings of the Measurements Code. The question was whether to attempt further delineation of the entries or to submit the draft to another outside reaction. The latter was the result of intensive deliberation.

In arranging for the field test the Committee accepted the fact that the first draft of the Impairment Code was necessarily only a first draft and that it contained a number of entries which were inconsistent with the accepted definition of visual function. These were the entries for right and left eye separately and for right and left eye by ranges of Snellen measurements. In effect, by these inclusions the draft covered the "case" of the impairment of visual function: example:

(heading)	Absence of Visual Function
070	Both eyes
071	Right eye
072	Left eye

This is to say that in 071 there is no impairment in the left eye and in 072, in the right eye. But since the definition refers specifically to the binocular use of vision, entries 070, 071, and 072 are inconsistent, and a single entry for what is here shown as the heading Absence of Visual Function should be numbered 070 and shown as the sole entry. Once there is measurable vision in either eye, it cannot consistently be said that there is "absence" of the use of (any) vision. The problem consists of the continuing influence of the traditional way of thinking about defects of vision and measurements indicating limitation of vision, as if they were impairments of "seeing."

The additional problem in trying to re-orient professional personnel to use a new approach was the danger of moving too far too fast. While the Rehabilitation Codes project concept was to intermesh differing information within an integrated records system, which would require that both the Impairment Code and the Cause Code (ICDA) be used, the Chairman of the Surgeon General's Subcommittee on the Physical Impairment Code presented the view that an Impairment Code which stood alone would have considerable interest to the government agencies with whose services he was concerned (the Armed Forces). If a certain amount of duplicatory information was contained in separate codes no harm was done to the records and on occasion a certain amount of verification would result. In addition, a new structure with familiar elements might secure acceptance more quickly, and over time, regular users would themselves see and slough off the duplicatory elements as they became familiar with more of the integrated sections within the records system.

A parallel was drawn then to similar anomalies remaining in the Impairment Code section on measured hearing, where decibel readings had been retained.

It was therefore decided to proceed slowly in completing a recommended code section which ultimately might achieve the desired end of re-orientation and acceptance in the field where professional practice was deeply entrenched.

The first step would be the field test examiner's reaction to recording the measurements of vision and then deriving from them selection of the Impairment Code entries to be recorded.

The examiner was David E. Brandt, M.D., of the Department of Ophthalmology, University Hospitals, The University of Iowa. The test was carried out on March 4, 5, 11, and 12, 1968 at the Iowa Braille and Sight Saving School. Thirty high school and junior high school pupils served as test subjects. A number of details in his report related to suggestions for adapting the Measurements procedures to fit the problems found in these young people.

1. An attempt was made to measure all near acuities at 14 but many subjects could only see the reduced Snellen chart at a much shorter distance, which had to be determined in each instance.

2. Ocular motility was tested by the examiner moving his finger up, down, nasally, and temporally, while the corneal reflex was noted with a flashlight held in the straight forward position.

3. The Worth 4-dot test was used at near (14 inches) to determine the presence or absence of fusion. When presense was found, stereopsis was testing using the Titmus Stereotest. Tropias could mostly be noted only by the Hirschberg reflex methods, after attempts to measure.

4. Color vision was evaluated with twenty A-O HRR pseudoisochromatic plates: in addition, green, yellow, blue, and red sheets of paper were presented when the first procedure indicated diminished color vision.

5. Visual fields were plotted with the tangent screen (Auto-Plot, Bausch and Lomb Co.) at one meter. In many subjects only gross confrontation fields could be outlined, while in others only the field of vision with light projection could be determined.

6. Most of the subjects exhibited nystagmus, which made testing of tropias or phorias almost impossible (these had to be estimated using the Hirschberg method) and evaluation by tangent screen difficult because central fixation was a problem. Plotting of blind spots in many instances was at best an estimate.

7. Many of these subjects attained their best near acuity at two to six inches, which is not considered physiologic. The examiner noted that this is often reported. Since the Measurements Code did not provide for such distances, he recorded the line of the reduced Snellen chart which was read (example: 20/800 at 4 inches), omitting the Measurements Code number, which was for 6 inches.

8. The examiner questioned the omission in the Measurements Code of an entry signifying "no defect of color vision" since in other areas of vision, the entire range of function possible was covered. (This oversight was noted for correction.)

9. The examiner stated that the Impairment Code "was easier to interpret" than the Measurements Code.*

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*All the young subjects in this field test were in the upper educational grades at the Iowa School and already completely independent in their self-care and other daily activities. As a result, the self-care activities check list was not used; in addition, since none was of a home-making age or living at home, the list for those activities also was not applicable.

No. _ _ Initials ___ ___ ___ Date field test examination _ _ _ _ _ _
Age _ _ Birthdate _ _ _ _ _ _
Onset of complaint: Age _ _ Date of onset _ _ _ _ _ _
"Legally blind" certified: Age _ _ Date of certification (1st) _ _ _ _ _ _
most recent
Diagnosis: ______________________________

Measurements						Adaptation procedure
Central vision	uncorrected	code	corrected	code	test object at	
distance						
both	/	_ _ _	/	_ _ _	____	______
right	/	_ _ _	/	_ _ _	____	______
left	/	_ _ _	/	_ _ _	____	______
near						
both	/	_ _ _	/	_ _ _	____	______
right	/	_ _ _	/	_ _ _	____	______
left	/	_ _ _	/	_ _ _	____	______
Motility	degrees	code			test object	
right						
up	____	_ _ _			____	______
nasal	____	_ _ _			____	______
temporal	____	_ _ _			____	______
down	____	_ _ _			____	______
left						
up	____	_ _ _			____	______
nasal	____	_ _ _			____	______
temporal	____	_ _ _			____	______
down	____	_ _ _			____	______
Binocular vision	uncorrected degrees	code	corrected degrees	code	prisms	
onset of double vision	____	_ _ _	____	_ _ _	____	______
phoria: horizontal:						
distance		_ _ _		_ _ _	____	______
near		_ _ _		_ _ _	____	______
vertical:						
distance		_ _ _		_ _ _	____	______
near		_ _ _		_ _ _	____	______
Peripheral vision					test object at	
perimeter						
right	____	_ _ _	____	_ _ _	____	______
left	____	_ _ _	____	_ _ _	____	______
tangent screen						
right	____	_ _ _	____	_ _ _	____	______
left	____	_ _ _	____	_ _ _	____	______
Color vision					test used	
both	____	_ _ _	____	_ _ _	____	______
right	____	_ _ _	____	_ _ _	____	______
left	____	_ _ _	____	_ _ _	____	______

Cause ICDA

(100-152) Absence/limitation: distance	both	_ _ _	_ _ _ _
	right	_ _ _	_ _ _ _
	left	_ _ _	_ _ _ _
near	both	_ _ _	_ _ _ _
	right	_ _ _	_ _ _ _
	left	_ _ _	_ _ _ _
(153-155) Distortion affecting intelligibility of object seen	both	_ _ _	_ _ _ _
	right	_ _ _	_ _ _ _
	left	_ _ _	_ _ _ _
(156-170) Limitation and distortion:	both	_ _ _	_ _ _ _
	right	_ _ _	_ _ _ _
	left	_ _ _	_ _ _ _
(171-179) Impairment of color function	both	_ _ _	_ _ _ _
	right	_ _ _	_ _ _ _
	left	_ _ _	_ _ _ _
(180-183) Impairment of visual orientation		_ _ _	_ _ _ _
(184-190) Impairment of distance accommodation		_ _ _	_ _ _ _
(191-205) Distortion of visual field		_ _ _	_ _ _ _
(206-237) Impairment of binocular function		_ _ _	_ _ _ _
(238-249) Other disorders		_ _	_ _ _ _

All record forms used in the field test were returned to the Advisory Committee along with the examiner's critique. Again, all the materials were reviewed, revised, and re-issued. The draft of the Measurements Code, instructions for procedures, instrumentation, test conditions, and adaptations, and for the Impairment Code were approved for publication, in the hope that workers in the field would study and try to use them, and respond to the project request for reactions on their usefulness.

The Advisory Committee recommended that the Impairment of Visual Function code section be included in the overall Code draft for the Surgeon General's Subcommittee on the Physical Impairment Code.

Summary of Project

A two-year project to develop an Impairment Code section on Impairment of Visual Function involved continuous work by the Principal Investigator and the Advisory Committee to correct and refine standard measurements procedures and recommendations for instrumentation and test conditions: these had been developed by an earlier subcommittee working under the Rehabilitation Codes project. The aim was to take a further step beyond completion of the Measurements Code and derive therefrom, in a form consistent with the overall Impairment Code pattern already established, an Impairment Code for Visual Function stated in terms of the human function of "seeing"--that is, the uses of whatever vision may be available as indicated by following the recommended examination and recording standards.

Throughout the research period the current stages of the materials were submitted to outside specialist study and criticism, in the form of working conferences and field testing. Each exposure was followed by renewed efforts to clarify and refine the code drafts.

The final draft completed within the limited time provided for by the grant period was accepted by the Advisory Committee as a first attempt to produce a useful way of describing the effects of defective vision upon the person's ability to carry on his everyday life. The usefulness of the materials could be determined only by attempts among the workers in the field to apply the descriptions to their own clients, to secure more informative and reliable clinical reports, and hopefully to lead to accumulation of valid documentation for proposals of new legislation to replace the out-dated certification program for the "legally blind."

The first step would be for national adoption of professionally agreed upon standards for measurement of vision using specified instrumentation, procedures, and recording of detail in a form consistent with compilation of comparable data.

The next step would be for re-orientation of service programs from emphasis on the loss or limitation of function to equal consideration of the person's residual function, assets of education, morale, and experience, on which to capitalize in planning delivery of services. New enabling legislation for this purpose would assist in bringing service to people on the basis of up-to-date knowledge--clinical and behavioral--as to the adaptability of the human being and his educability in new skills for his everyday satisfying life.

Using the Impairment Code entries to interpret the meaning for the person of the clinicians' measurements of his vision would emphasize the human importance of performing to the limits of one's capabilities, requiring an evaluation of the person to be served, within the total picture of his accustomed life in his family, neighborhood, and community, and in his maximal and optimal future life to be sought through rehabilitation.

The third step after accurate clinical and personal evaluation would be the use of a longitudinal method of recording and maintaining all records so that the information found to be current at each date he is seen can be recorded consistently for periodic comparisons against the base-line of his initial evaluation. This would assess the effectiveness of service given, his response to it, the trend in his clinical status and response to any clinical treatment, his growth towards whatever goals he might be capable of reaching, etc. These comparisons would permit measurement of the quality of the services in terms of their effectiveness to the person served.

With these three steps adopted by workers in the field, the fourth step would be research on the accumulated records of individuals whose case histories had been recorded for the same factors and in the same terms. It could be determined then how each person was able to carry out daily activities with or without visual function. Families of related activities could then be correlated with the measured vision recorded for each person. This would permit the needed research on how he performs the various activities of his daily life safely and with sufficient ease of mobility, how he orients himself within his physical environment, how he recognizes objects and people, how he learns by reading recorded symbols such as letters and numbers, maps and other sources of information, how he coordinates hand and eye, how he measures distances and places two objects on same or different levels. These are the human visual needs, which should be covered in the final draft of an Impairment Code. That no research to determine these functions has as yet been organized might be considered to depend upon the more basic lack of reliable measurements of vision; or the lack of a focus for the workers in the field to pin their dissatisfaction with prevailing procedures upon.

In research and attempts to establish or revise terminology an essential task has proved to be the re-thinking which must precede the re-casting into words. The conceptualization leads to embodiment in new expression. Even changing the routine of establish procedures permits re-conceptualizing the rationale--perception of new relationships and new knowledge to be incorporated. Setting of professional standards requires that the established routine be questioned to examine what is in effect and whether some altered practice may be desirable at this date.

Clinical and social services have traditionally been patterned upon the professional's practice of his skills, rather than upon the needs of the human being whom the skill should be practised for. Institutions and agencies' records have--like professional case notes--reflected more their own need for administrative and fiscal uses, rather than a picture of the change in the person's status from that of someone in need to someone who, having received service, can now proceed to live independently again. For these reasons, the need to set standards for routine procedures--professional and administrative--involves re-focusing records from automatic writing down of habitual phrases to thinking first about what the purposes of records are and what their uses may be--first, for the person, second, to implement and keep track of his service and response, and third, to support the first two uses by adding whatever specialized detail is necessary to maintain contact with the person and his environment and the techniques used to serve him, and the means of seeing that service is carried to completion--this includes the funding and purchase of service.

An example of the effect of routine may be given from one of the field tests where the subjects included eight people certified as "legally blind." Referral of the person examined for rehabilitation was not the purpose of the clinician's report: some clinicians are not rehabilitation-minded primarily.

But the reports were filed in a rehabilitation program where the staff use color clues in training severely handicapped people. Of the eighteen certification reports, two only had any reference to the person having been tested for presence or absence of color vision. On the two certification records bearing details on color vision, both showed the clinician reporting absence. Yet during the field test examination both subjects were found able to detect red and green from across some twelve feet of the examination room, when the Principal Investigator enquired what color dress she was wearing.

In sixteen instances the clinician apparently did not test color vision or at any rate did not record any findings. In the two instances, his record was contradicted by a casual question and was then tested by the field test examiner and the presence of an important rehabilitation factor was confirmed. If testing for color vision were incorporated in a standard measurements procedure and its importance to a person's ability to move about safely or to handle implements effectively was emphasized in the statutory program which had rehabilitation as a basic tenet, the continuing dependence of visually impaired people would begin to be lessened and the cost of their maintenance in dependence would be invested in resorting them to as great a level of self-sufficiency as their untapped resources might permit.

Problems of Implementation of Standardized Procedures

Because of the ingrained clinical approach the problem of getting new examination procedures and standards accepted consistently across the country seemed difficult enough without expecting immediate interpretation of measurements in terms of impaired areas of human function which may be affected by deficits of vision. It was agreed that standard examination must precede other desired steps in re-orienting many examiners towards a rehabilitation point of view, especially as long as the statutory program continued in its present form. Whereas what eventually must be determined by research is the specific visual functions, such as orientation in space and safe movement, which a person actually performs with his measured vision findings. Taken one person at a time, the accumulated information can then be analyzed to provide an entire "family" or range of activities which can be related to the range of measurements which were diagnosed: this is the reverse of the current practice of arriving at a measurement, and then without further documentation expecting that certain activities will inevitably be barred for an individual.

Until the date when the needed research can be carried out, the committee agreed that formulation of the standards for the examination procedures and records was a definitive step forward.

Adoption and use could lead to new legislation to replace certification as "legally blind"--that is, eligible for certain protections and benefits under federal law. And at the same time familiarization with new standards would lead examiners to look further into the uses which people must make of their vision. Adoption of new definitions and terms would influence them to consider what services might improve that use, and where identification of the uses began to be accepted, those large areas of human function exposed as "use areas" could become known as the areas which are impaired. The overall re-orientation could be expected to take several years, while workers in the field must continue to keep their needs well forward in examiners' attention and to press for change as rapidly as public and professional opinion can be moulded.

After a period of time, it was recommended that periodic re-study of the accumulated experience should lead to revision and further development of the coding materials, under whatever auspices might be organized at that date.

Meanwhile the project drafts would be recommended to the field for trial as tools of potential value to improved services for the visually impaired.

A recommended pattern of information which is presented for consideration by workers in the field would consist of the following elements, all of which are complementary the one to the other and any one of which presents only a fragmentary evaluation for rehabilitation:

1. standardized examination findings secured by means of a protocol such as is here presented for the Measurements Code;

2. interpretation of the effects of the totality of clinical findings in terms of impairment of the human function of "seeing," as shown in the first recommended draft of the Impairment Code;

3. the cause or causes--immediate (proximate) and underlying (distal)--of the defect, disease, or trauma, as coded under the International Classification of Diseases Adapted for Hospitals (ICDA);

4. description of the personal, social, and environmental factors which affect or contribute to the use of residual vision or the problems of adjustment in a world of "sighted" persons;

5. establishment of information on the particular activities which the particular person having the particular problems can or cannot do, under the living conditions of his home, neighborhood, and community;

6. incorporation of all information upon a longitudinal record form which will permit evaluation of the person's current status at each of the successive dates when he is seen throughout his rehabilitation services and upon follow-up thereafter over whatever period of time may be required to ensure his maximal and optimal independence.

The text of the materials developed in this research project follows.

GENERAL DEFINITIONS AND PRINCIPLES

Definitions

Vision is the sensory reception of visual stimuli.

Visual function implies the binocular use of the sense of vision.

Measurement of Vision

The Measurements Code provides standards for clinical examination of vision, using stipulated procedures, instrumentation, and test conditions of environment, with findings expressed in the measurements as indicated by coded entries for the areas

1. central vision
2. visual field
3. binocular vision
4. ocular motility
5. color vision

Measurements of vision are expressed in deviations from accepted standards or "norms," but such deviation does not directly imply a resultant impaired function for "seeing"--which is the use of existing vision. The measurement 20/20 for central vision can actually be evidence of a deviation where the person initially had vision measured at 20/10. All measurements of vision must be combined for the derivative interpretation in terms of impairment. Any "norm" is understood--not as unimpaired function but as a statistical average; and because all evaluations of visual function are individualized, the term is not relevant in this research project.

Entries in the Measurements Code and Impairment Code bear no relation to measurements designated elsewhere for "legal blindness" or "industrial blindness," etc. Here the intention is to describe the vision and visual function exhibited at one date examined under standards stipulated for procedures, instrumentation, and test conditions. Repeated examinations for the same person must be carried out under the same standards to provide a valid comparison of findings.

Description of Impairment of Visual Function

The impairment of visual function is derived from the totality of all clinical examination findings at a stipulated date. All impairment is expressed in terms of binocular use of vision, according to the defects found on standard examination.

The term "blindness" is not used in the Impairment Code. It could be related to only one entry for absence of binocular function, since any perception of light in one eye provides some evidence upon examination, although the amount may not be measurable. Absence means total impairment of visual function.

The Cause Code

The International Classification for Diseases Adapted for Hospitals is used to provide information on the causative developmental condition, or disease or trauma. An immediate or proximal cause and, as relevant, an underlying or distal cause may be coded to indicate the static or dynamic condition to be provided clinical treatment. Example: cataract coded 374 excludes diabetic cataract. 374 (immediate cause of a stated diminution of vision) would be followed by 250 diabetes mellitus (underlying disease).

Recording of Examination Procedures

All recommended distances, sizes and colors of test objects, use of tangent screen, etc., are details to be recorded to indicate the means by which the findings were secured. Where any standard procedure is deviated from, because of the problems of a particular person's vision, there is space provided for entry of adaptations of the procedures.

Serial dating When an examination is carried out, all findings are entered in a column headed by that date. Parallel columns are provided on the longitudinal record form, so that at each examination the new date and findings are recorded in parallel spaces for the entries of the earlier examinations: this provides for immediate comparison and ascertainment of the trend in status and/or response to therapeutic procedures which may be carried out.

Where no measurement is possible, enter an X in each space provided for recording and coding.

INSTRUCTIONS

TESTING PROCEDURE

Distance Vision

1. Place chart at standard distance - 20 feet.
2. For vision lower than 20/2000 place the chart at any fixed distance between 20 feet and 1 foot. Record the distance used.
3. For vision lower than 20/4000 (1/200) state the finding in terms of:
   a. light perception with accurate monocular projection in stated quadrants. Record light source and distance.

   b. light perception without accurate projection.

   c. no light perception.

Near Vision

1. For near vision equivalents of 20/20 down to and including 20/200, hold standard reading card at 16 inches (40 centimeters).
2. For near vision lower than the equivalent of 20/200 down to 1/200 start measuring at 16 inches (40 centimeters) and if necessary bring the reading card closer. Record the distance.

SERIAL RECORD

Wherever stipulated standard distance is not used, record the distance used.

When a vision aid is used, record the type; record the distance of the aid from the chart, its type, and magnification.

For all findings at one date, record in column headed by that date, with subsequent parallel findings similarly entered.

Note that the Measurements Code numbers run from 001-up, while the Impairment Code numbers start at 070 because they are a section of the overall Impairment Code.

INSTRUCTIONS

MEASUREMENT OF VISION

Measurements should be made for both near and distance vision for each eye separately and for both eyes together. Starting with

1. the unaided eye
2. the existing ophthalmic lens correction in use if any
3. the best ophthalmic lens correction for refractive and accommodative deficiencies

4. the best vision aid.

recording all prescriptions, and the type of aid used in (4).

Distance Vision	Near Vision
The standard for measurement is 20 feet (6 meters).	The standard for measurement is 16 inches (40 centimeters).
INSTRUMENTATION	
Use	Use Near cards containing
1. Vision charts 2. Vision projectors 3. Vision testing instruments 4. Two-cell flashlight	1. Reading matter with letters grouped into words and sentences 2. Isolated characters
TEST CHARACTERS	
1. Snellen letters or equivalent 2. Landolt rings 3. Tumbling E's	1. Letters: lower case in standard print. 2. Landolt rings 3. Numbers
ILLUMINATION	
1. Illumination of the chart: 15-25 foot-candles 2. Black/white contrast 85% 3. Room illumination 10-12 foot-candles	1. Illumination of the reading material: 20-25 foot-candles 2. Black/white contrast 85% 3. Room illumination 10-12 foot-candles

MEASUREMENT OF VISION

001	no light perception
	Inability to localize light perceived
002	Light perception without any projection
003	Two-light discrimination only
	Inability to localize light in quadrants
004	In all four quadrants
005	Upper/lower temporal and lower nasal quadrants
006	Upper/lower temporal and upper nasal quadrants
007	Lower temporal and upper/lower nasal quadrants
008	Upper temporal and upper/lower nasal quadrants
009	Upper and lower nasal quadrants
010	Lower temporal and upper nasal quadrants
011	Upper temporal and lower nasal quadrants
012	Lower temporal and lower nasal quadrants
013	Upper temporal and upper nasal quadrants
014	Upper and lower temporal quadrants
015	Lower nasal quadrant
016	Upper nasal quadrant
017	Lower temporal quadrant
018	Upper temporal quadrant

APPROXIMATE EQUIVALENT MEASUREMENTS OF CENTRAL VISION

Code # Distance	min. of arc	20ft.(6m.)	variable distances	40cm.(16in.)	14in.(35cm.)	Code # Near
020	200.	20/4000	1/200	40/8000	14/2800	050
021	160.	20/3200	1.25/200	40/6400	14/2440	051
022	125.	20/2500	1.5/200	40/5000	14/1800	052
023	100.	20/2000	2/200	40/4000	14/1400	053
024	80.	20/1600	2.5/200	40/3200	14/1120	054
025	65.	20/1250	3/200	40/2500	14/900	055
026	50.	20/1000	4/200	40/2000	14/700	056
027	40.	20/800	5/200	40/1600	14/560	057
028	32.	20/650	6/200	40/1300	14/450	058
029	25.	20/500	8/200	40/1000	14/350	059
030	20.	20/400	10/200	40/800	14/280	060
031	16.0	20/320	12.5/200	40/640	14/225	061
032	12.5	20/250	16/200	40/500	14/175	062
033	10.0	20/200	20/200	40/400	14/140	063
034	8.0	20/160		40/320	14/122	064
035	6.25	20/125		40/250	14/87.5	065
036	5.0	20/100		40/200	14/70	066
037	4.0	20/80		40/160	14.56	067
038	3.0	20/60		40/120	14.42	068
039	2.5	20/50		40/100	14/35	069
040	2.0	20/40		40/80	14/28	070
041	1.5	20/30		40/60	14/21	071
042	1.25	20/25		40/50	14/17.5	072
043	1.0	20/20		40/40	14/14	073
044	0.8	20/16		40/32	14/12	074
045	0.65	20/13		40/26	14/9.1	075
046	-	20/10	-	-	-	076

INSTRUCTIONS

MEASUREMENT OF VISUAL FIELD

Use standard clinical procedures for determining the location and measurement of visual field. Measure each eye separately.

Test Objects

For perimeter measurement, use 3 millimeter white test object at 300 millimeters or equivalent.

For tangent screen measurement, use 1 millimeter white test object at 1000 millimeters.

If circumstances require using larger test objects or different distances, record the adaptation as used. Plot extent of location on the screen. In the case of very poor vision, the confrontation method may be required.

Record the size, type, and color of test objects, the distances, and the instrumentation used.

The minimum extent in degrees of visual field from point of fixation is shown for each of the eight 45° meridians:

	Perimeter	Tangent Screen
temporally	85	25
down temporally	85	25
down	65	25
down nasally	50	25
nasally	60	25
up nasally	55	25
up	45	25
up temporally	55	25

The following types of defect should be determined:

- central
- peripheral constriction
- temporal
- nasal
- inferior
- superior or ring

Perimeter Measurement

080	Binocular	560-401	degrees	Degrees shown express the amount of lost function.
081		400-301		
082		300-151		
083		150- 0		
084	Right eye	500-401		Perimeter and tangent screen measurements shown here for right and left eyes are equivalent for the four parallel levels.
085		400-301		
086		300-151		
087		150- 0		
088	Left eye	500-401		The findings for binocular are a combination of findings for both eyes, examined separately.
089		400-301		
090		300-151		
091		150- 0		

Tangent Screen Measurement

092	Right eye	240-181	degrees
093		180-121	
094		120- 61	
095		60- 0	
096	Left eye	240-181	
097		180-121	
098		120- 61	
099		60- 0	

INSTRUCTIONS

MEASUREMENT OF BINOCULAR VISION

Double Vision

Use a flashlight noting the present of double vision in the primary or other positions. Record the absence or presence and the positions of gaze in which the finding is determined.

Test Conditions

Measure at distance and near, using standard procedures:

stereopsis use
1. major amblyoscope
2. clinical stereoscope
3. the Wirt Stereo test
4. the modified Verhoeff Depth Perception Test

phorias use
1. Maddox rod
2. loose or rotary prisms
3. prism bar test

(Vertical phoria should be tested at 20 degrees and at the comfortable reading position.)

No binocular vision

100 Near and distance
101 Near
102 Distance

Simultaneous perception without fusion or stereopsis

103 Near and distance
104 Near
105 Distance

Fusion without stereopsis

106 Near and distance
107 Near
108 Distance

Lateral phoria

109 Near, exceeding 2^{Δ}eso or 4^{Δ}exo not compensated by the applicable vergence measurement equal to twice and phoria value
110 Distance, exceeding 2^{Δ}eso or 4^{Δ}exo not compensated by the applicable vergence measurement equal to twice the phoria value

Vertical phoria exceeding 2^{Δ}

111 Near
112 Distance
113 Combinations of lateral and vertical phoria: 109, 110, 111, and 112

Double vision

114	0 - 5 degrees
115	6 - 15
116	16 - 25
117	26 - 35
118	36 - over

Degrees shown express the amount of vision present.

INSTRUCTIONS

MEASUREMENT OF OCULAR MOTILITY

Test right eye and left eye separately for ductions in the four meridians, head fixed. Use a perimeter to record the degrees of motion in each meridian.

Up

119	0 - 5 degrees
120	6 - 15
121	16 - 25
122	26 - 35
123	36 - over

Excursions for each eye are shown in terms of degrees of vision present in each meridian.

Nasal

124	0 - 5 degrees
125	6 - 15
126	16 - 25
127	26 - 35
128	36 - over

Temporal

129	0 - 5 degrees
130	6 - 15
131	16 - 25
132	26 - 35
133	36 - over

Down

134	0 - 5 degrees
135	6 - 15
136	16 - 25
137	26 - 35
138	36 - 45
139	46 - over

INSTRUCTIONS

TEST FOR COLOR VISION

Use American Optical Company HRR pseudo-isochromatic plates with MacBeth easel lamp.

When vision is defective it may be necessary to use the Worth 4-dot colors at 40 centimeters.

	Total monochromacy	
150	Typical	For both eyes together
151	Atypical	
	Perception of red	
	right eye	
152	No perception of red	For each eye separately
153	Limited perception of red	
	left eye	
154	No perception of red	
155	Limited perception of red	
	Perception of green	
	right eye	
156	No perception of green	
157	Limited perception of green	
	left eye	
158	No perception of green	
159	Limited perception of green	
	Perception of blue	
	right eye	
160	No perception of blue	
161	Limited perception of blue	
	left eye	
162	No perception of blue	
163	Limited perception of blue	
164	Inability to discriminate among colors when vision is insufficient to use HRR test	For both eyes together
	Acquired defect of color vision	
165	Both eyes	For each eye separately and for both eyes together
166	Right eye	
167	Left eye	
169	No defect of color vision	
	Absence of Visual Function	
070		Visual function implies the binocular use of the sense of vision.
	Light Detection below Measurable Levels	
	Limitation of Ability to Detect Light	
071	Both eyes	
072	Right eye	
073	Left eye	
	Limitation of Ability to Locate Light	
074	Both eyes - nasal up	In quadrants
075	- nasal down	

076 - temporal up
077 - temporal down
078 Right eye - nasal up
079 - nasal down
080 - temporal up
081 - temporal down
082 Left eye - nasal up
083 - nasal down
084 - temporal up
085 - temporal down

Absence of Two-Light Discrimination

086 Both eyes
087 Right eye
088 Left eye
089 Impairment of Light Detection Below Measurable Levels NEC/NOS (NEC/NOS = not elsewhere covered/not otherwise specified)

Distance Vision - Both Eyes

090 20/4000 - 20/1250
091 20/1000 - 20/400
092 20/320 - 20/125
093 20/100 - 20/40
094 20/30 - 20/13

The ranges of measurements shown here are arbitrary. Revision towards statement in terms of binocular function requires research on significant function related to performance of specific activities.

Distance Vision - Right Eye

095 20/4000 - 20/1250
096 20/1000 - 20/400
097 20/320 - 20/125
098 20/100 - 20/40
099 20/30 - 20/13

Distance Vision - Left Eye

100 20/4000 - 20/1250
101 20/1000 - 20/400
102 20/320 - 20/125
103 20/100 - 20/40
104 20/30 - 20/13

Distance Vision - Both Eyes

105 20/4000 - 20/1250
106 20/1000 - 20/400
107 20/320 - 20/125
108 20/100 - 20/40
109 20/30 - 20/13

Near Vision - Right Eye

110 20/4000 - 20/1250
111 20/1000 - 20/400
112 20/320 - 20/125
113 20/100 - 20/40
114 20/30 - 20/13

Near Vision - Left Eye

115 20/4000 - 20/1250
116 20/1000 - 20/400
117 20/320 - 20/125
118 20/100 - 20/40
119 20/30 - 20/13

Impairment of Visual Field Function

By site

120 Right Eye - central
121 - concentric
122 - temporal
123 - nasal
124 - inferior
125 - superior
126 - ring
127 Left Eye - central
128 - concentric
129 - temporal
130 - nasal
131 - inferior
132 - superior
133 - ring
134 Impairment of Visual Field Function NEC/NOS

Impairment of Binocular Function

Absence of Binocular Function

135 Near and distance vision
136 Near vision
137 Distance vision

Each level shown here from stereopsis to fusion requires the unimpaired function of all previous levels.

Absence of superimposition

138 Near and distance vision
139 Near vision
140 Distance vision

Binocular function implies at distance and near, presence of

1. simultaneous perception (seeing with each eye separately but at the same time)
2. ability to superimpose separate images of the same object to achieve fusion
3. full fusional range
4. stereopsis

Absence of fusion

141 Near and distance vision
142 Near vision
143 Distance vision

Absence of stereopsis

144 Near and distance vision
145 Near vision
146 Distance vision

Limitation of Binocular Function

Limitation of fusional range

147 Near and distance vision
148 Near vision
149 Distance vision

Limitation of stereopsis

150 Near and distance vision
151 Near vision
152 Distance vision

Intermittent Binocular Vision

Simultaneous perception

153 Near and distance vision
154 Near vision
155 Distance vision

Superimposition

156 Near and distance vision
157 Near vision
158 Distance vision

Fusion

159 Near and distance vision
160 Near vision
161 Distance vision

Stereopsis

162 Near and distance vision
163 Near vision
164 Distance vision

165 Impairment of Binocular Function NEC/NOS

Impairment of Monocular Motility

170 Right eye - nasal up   By quadrant: loss exceeding 20°
171 - nasal down
172 - temporal up
173 - temporal down
174 - combinations of 170-173
175 Left eye - nasal up
176 - nasal down
177 - temporal up
178 - temporal down
179 - combinations of 175-178
180 Impairment of Ocular Motility NEC/NOS

Impairment of Color Function

Absence of Color Function

181 Absence of color discrimination   For both eyes together
182 Absence of red discrimination
183 Absence of green discrimination
184 Absence of blue-yellow discrimination

Limitation of Color Function

185 Limitation of color discrimination
186 Limitation of red discrimination
187 Limitation of green discrimination
188 Limitation of blue-yellow discrimination

189 Impairment of Color Function NEC/NOS

Other Disorder of Visual Function

Only where unmeasurable by 090-119

Impairment of Sensitivity to Brightness

190 Excessive sensitivity to brightness
191 Limitation of sensitivity to brightness

Interference to Continuity of Visual Function

tearing
192 Absence of tearing
193 Excessive tearing

blinking
194 Excessive blinking
195 Absence of blinking

196
197
198
199 Impairment of Visual Function NEC/NOS

AAWB
Blindness

983

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INCORPORATED 1955